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The experiences of bio-psycho-social adaptation following a diagnosis of type 1 diabetes in adulthood

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**THE EXPERIENCES OF BIO-PSYCHO-SOCIAL
ADAPTATION FOLLOWING A DIAGNOSIS OF
TYPE 1 DIABETES IN ADULTHOOD**

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Abstract

A diagnosis of type 1 diabetes in adulthood is a major disruption to habitual life and demands significant physical and psychosocial adaptation. The strategies employed during this adaptive phase may have an important impact on the future risk of diabetes complications and psychological well-being. To date, little consideration has been given to the experiences of adults following diagnosis, even though more than half of all cases of type 1 diabetes occur in adulthood. Therefore, to better understand and attend to the needs of adults at and following their diagnosis, this study aimed to explore the experience of being diagnosed with type 1 diabetes in adulthood. The study sought to elicit the underlying bio-psycho-social phenomena that may influence the process of adaptation when becoming a person with diabetes, to identify areas that could be targeted to facilitate a more positive adaptive process.

Longitudinal semi-structured interviews were conducted with 30 adults (age range 20-67 years; 16 men; median diabetes duration 23.5 months) recruited from diabetes clinics in Denmark and the UK. A narrative approach was used to analyse the interview data thematically. The study findings were then synthesised to model potential pathways for intervention.

Study participants identified that adapting to diabetes was a multi-dimensional process occurring over a long period of time. Two overarching and interrelated elements were identified within this process: learning about diabetes and learning to live with diabetes. Learning about diabetes encompassed the technical skills and knowledge required to self-manage their treatment on a daily basis. Learning to live with diabetes involved recognising the uniqueness of diabetes in terms of its enduring and all-encompassing nature, and understanding the way diabetes influenced their self-identity, their social relationships and their engagement in the wider society. The findings suggest that most of the support provided to the participants in their early disease experience was focussed on learning about diabetes rather than how to live with it.

The failure to attend to patients' emotional reactions to diabetes or equip them with the skills necessary for a life with diabetes, may lead to the development of unhelpful behaviours and a tendency to disassociate from diabetes. The findings of this study suggest that enhanced psycho-social intervention during this early 'fluid' phase of the disease may be important in preventing the development of harmful emotional responses and the habituation of behaviours that may increase their risk of complications and reduce their short and long-term well-being. Such interventions need to be instigated from the point of diagnosis, with a focus on developing positive adaptive strategies and thinking styles.

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Chapter 1 Introduction

This thesis details a study exploring adaptation to life with type 1 diabetes in adults recently diagnosed with the condition. The study explores the influence of bio-psycho-social phenomena on the process of adaptation to identify potential mechanisms that could be used to enhance the support provided and foster more positive adaptive strategies following a diagnosis of type 1 diabetes in adulthood. To widen the perspective of the study in relation to the experiences explored, the study was conducted in populations in Denmark and the UK.

Rationale for the study

Type 1 diabetes is an autoimmune disease where destruction of the insulin-producing beta cells in the pancreas leads to metabolic instability following the loss of insulin secretion over a period of time (Thrower and Bingley 2014, Atkinson et al. 2014). This instability eventually leads to hyperglycaemia, producing symptoms such as weight loss, excessive thirst, polyuria and lethargy. The severity of these symptoms can vary between patients and some will become acutely unwell developing diabetic keto acidosis (DKA) prior to diagnosis. While the exact causality of the autoimmune destruction of beta cells is unknown, genetic, epigenetic, and environmental factors have been identified as possible contributors to the development of the disease (Atkinson et al. 2014, Tuomilehto 2013). Type 1 diabetes is fatal unless treatment with insulin is initiated when the diagnosis is established.

The incidence of type 1 and type 2 diabetes is increasing; current global estimates suggest that there are around 415 million people with the disease, although this varies significantly between countries (IDF 2015). Latest estimates suggest that there are 32.000 and 285.000 people living with type 1 diabetes in Denmark and the UK, respectively. This is equivalent to approximately 0.4% prevalence in the general population and accounts for up to 8.5-10% of all people living with diabetes (Jørgensen et al. 2016, Holman et al. 2015).

Type 1 diabetes is associated with increased morbidity and mortality, with both microvascular and macrovascular damage resulting in high levels of kidney failure,

blindness, lower limb complications and cardiovascular disease (Atkinson et al. 2014). However, such outcomes can be avoided or minimised if the patient's blood glucose levels can be near-normalised with exogenous insulin therapy. The Diabetes Control and Complications Trial (DDCT), a randomised controlled trial involving 1441 people (mean age 27.1 years) recently diagnosed (mean duration 2.6 years) with type 1 diabetes, found that tightening glycaemic control to a glycated haemoglobin (HbA1c) of <7% with intensive insulin treatment significantly reduced the risk of both micro and macro vascular complications (DCCT group 1993). The long term follow up of participants in this study in the Epidemiology of Diabetes Interventions and Complications study (EDIC), found that those in the intensive treatment group continued to have lower levels of complications and mortality compared to those in the control group 20 years after the intervention, suggesting that this period of good metabolic control had an enduring effect, the so called 'metabolic memory' (Pirola 2014, Nathan et al. 2013, Nathan and Group 2014). Other studies have found that intra-personal levels of glycaemic control three to twelve months after diagnosis seem to be stable and predictive of glycaemic control five years later (DeVries et al. 2004, Jorde and Sundsfjord 2000, Hesse and Ridderstråle 2014). These findings suggest that glucose control in the early post-diagnostic phase may have an important impact on long term outcomes for people with type 1 diabetes.

Type 1 diabetes is generally associated with childhood or early adolescence, where the peak incidence occurs (Hodgson et al. 2012, Svensson et al. 2009, Tuomilehto 2013). However, it has been estimated that around half of people living with type 1 diabetes are diagnosed in adulthood (Ostman et al. 2008, Tuomilehto 2013, Thunander et al. 2008, Bruno et al. 2016, Diaz-Valencia et al. 2015, Thomas et al. 2016, Molbak et al. 1994). Despite this fact, there are limited data on this population in terms of the impact of being diagnosed with diabetes (Feltbower et al. 2003, Gonder-Frederick et al. 2002).

The physiological changes and initiation of insulin treatment necessitated by the diagnosis of type 1 diabetes demand significant adaptation. In studies of adults with longer diabetes duration, the process of adapting to a life with diabetes has been

described as ongoing and multifaceted (Whittemore and Roy 2002, Hernandez 1996, Paterson et al. 1999). Adaptation can also be defined as a process through which an individual uses a range of cognitive, emotional, behavioural, and psychological strategies to promote and maintain their well-being and good quality of life when faced with a new life situation (Taylor 1983, Livneh 2001, Sharpe and Curran 2006). These strategies also encompass developing new routines and automating actions that may enhance their adaptive process (Cohen and Lazarus 1979). In the context of type 1 diabetes this involves the development of new competences that a life with type 1 diabetes demands, such as insulin injection and blood glucose measurement. The paraphernalia required for these behaviours make the disease visible to others and are symbols of change which potentially create a sense of division between the person with diabetes and those around them (Goffman 1963). This in turn calls for major personal and social adaptations (Whittemore and Roy 2002, Hernandez 1996, Beran 2014, Lundman and Norberg 1993, Paterson et al. 1998). These complex and time-consuming behaviours have to be developed rapidly during a period of physical and emotional turmoil. This formative period of adaptation to diabetes may be important in shaping an individual's future transition into a life with diabetes, their level of engagement with the disease and ultimately their long-term psychosocial well-being and risk of complications.

While there have been many studies examining the psychosocial impact of a diabetes diagnosis on children (Herrman 2006, Kelo et al. 2011, Lambert and Keogh 2015), adolescents (Hema et al. 2009, Chilton and Pires-Yfantouda 2015) and their families (Niedel et al. 2013, Wennick and Hallstrom 2006, Husted et al. 2014)), there have been very few considering the impact of diabetes on adults (≥ 18 years) diagnosed with type 1 diabetes. Also, knowledge about the process of adaptation to a life with diabetes in adults during the first three years after diagnosis is scarce.

A diabetes diagnosis in childhood requires multiple adjustments for the child and the family (Rearick et al. 2011). Due to developmental issues it is often the parents who are responsible for treatment and for facilitating the necessary changes (Ginsburg et al. 2005). When a person is diagnosed in childhood or adolescence they are familiar with diabetes when entering adulthood (Rasmussen et al. 2011). Compared to children and

adolescents the needs of adults are distinct, as their life experiences and perspectives are more developed, and the disease may have a significant impact on employment, economic well-being and relationships (Lašaitė et al. 2016). However, knowledge is lacking concerning the needs and experiences of the adult onset population following their diagnosis of type 1 diabetes when considering their adaptation to a life with diabetes.

Therefore, if the care needs of this population are to be met we need a better understanding of those needs and experiences in order to develop strategies to facilitate early adaptation to the disease. Studies exploring aspects of adaptation to diabetes in adults with longer duration of diabetes (Paterson et al. 1998, Hernandez 1996, Booker et al. 2008, Ingadottir and Halldorsdottir 2008, Campbell et al. 2003), suggest that living with diabetes is an ongoing process with a focus on trying to balance their lives with the effects of the disease. However, despite recent advances in insulin treatment and technological support, less than half of adults with type 1 diabetes achieve the recommended treatment targets for blood glucose necessary to avoid disease complications (McKnight et al. 2015). It would seem that accommodating the demands of diabetes within a person's life is challenging. The challenge is also evident in the psychological problems found in this population with high levels of depression (Barnard et al. 2006, Pouwer 2017) and diabetes distress (Sturt et al. 2015, Zoffmann et al. 2014, Bjarkøy Strandberg et al. 2015, Mohn et al. 2015). It may be that some of these difficulties have their origins during the initial process of adapting to a life with type 1 diabetes.

There are some data showing how bio-psycho-social factors may independently explain variations in adaptation and clinical outcomes in the longer term. Biologically, the honeymoon period with variations in the rate of decline in insulin secretion may significantly affect glycaemic control (Tsai et al. 2006). Socially, support has been found to influence self-management behaviours (Kovacs Burns et al. 2013, Rintala et al. 2013b, Joensen et al. 2013, Trief et al. 2017). Psychologically, factors such as patients' higher levels of perceived self-efficacy (Sousa et al. 2005), resilience (Celano et al. 2013), and sense of coherence (Ahola et al. 2012) have been shown to positively influence self-management behaviours and quality of life. The failure to attend effectively to these

challenges at an early stage may have an enduring effect on long term outcomes for people with type 1 diabetes. It could be assumed that early support regarding bio-psycho-social adaptation to life with diabetes may positively affect self-management behaviours, glycaemic control, risk of complications, psychosocial well-being and quality of life, leading to better long-term outcomes in all of these domains for people with type 1 diabetes. Therefore, developing a better understanding of people with type 1 diabetes' views and experiences at the time of their diagnosis and in the early phase of the disease will help identify the bio-psycho-social phenomena influencing adaptation.

This study aims to explore the experiences of adults in relation to being diagnosed with type 1 diabetes and their adaptation to life with the condition to identify some of the underlying phenomena and mechanisms that influence the process of adaptation. The study will use this understanding to engineer a framework for a supportive intervention.

The Medical Research Council's (MRC) complex evaluation framework is used to inform the study design (Craig et al. 2008). It consists of four key elements: development; feasibility and piloting; evaluation; and implementation. In this exploratory study the focus is on the development phase, which entails identification of the evidence base, and gaining knowledge to develop the theoretical and modelling phases of the framework. Qualitative findings from personal narratives will be used to model the framework.

The study is undertaken in collaboration between the Faculty of Nursing and Midwifery King's College London and Diabetes Management Research at Health Promotion Research Steno Diabetes Center, Copenhagen. Data have been collected in two clinical settings in the UK and three clinical settings in Denmark.

Overview of the thesis

The thesis consists of seven chapters. The rationale for the study is provided in the introduction chapter. Chapter 2 provides the background for the study. Firstly, general

theoretical constructs applicable to the study questions are presented. These theoretical constructs are adaptation and the bio-psycho-social framework. Secondly, a systematic review and meta-synthesis of current qualitative literature exploring the experiences of being diagnosed with type 1 diabetes in adulthood is presented. Finally, a review of current intervention studies and programmes targeting new onset type 1 diabetes in adults is presented. Chapter 3 outlines the rationale for the study design and approach as well as the methods used in the study. The findings from the explorative study are presented in chapters 4, 5 and 6. Chapter 4 presents the characteristics of the study participants and findings in relation to the transnational aspects of the study. Chapter 5 is the main findings chapter, presenting the diabetes story as described in the participants' narratives. Chapter 6 outlines potential models to underpin the intervention framework. Chapter 7 contains a discussion of the findings, including strengths and limitations of the study, followed by implications for practice and future research.

Chapter 2 Literature review

This chapter provides the background for the study and identifies current knowledge and theory relevant for the conduct of the study. The chapter outlines the general theoretical constructs that have been used to inform the study approach; the two primary constructs for the study are adaptation and the bio-psycho-social model. Therefore, the background to these theories and their application within the study are explained. The chapter also incorporates a systematic review and meta-synthesis of studies exploring the experiences of being diagnosed with type 1 diabetes in adulthood. Finally, the chapter presents a review of current intervention studies and programmes targeting new onset type 1 diabetes in adults.

Theoretical perspectives

The two core concepts used to inform the study are adaptation and the bio-psycho-social model. These concepts have been chosen as they provide a useful lens for studying a person's experiences following a diagnosis and transition into a life with type 1 diabetes.

Adaptation

There are a number of theoretical models of adaptation, these models consider both biological and psychosocial adaptation within the natural sciences, psychology and sociology. For this thesis the main interest is in the theories relating to psychological adaptation. The psychological theories of adaptation have generally defined adaptation as a response to an event or a stressor in the environment that imposes changes on the person's present state and how these integrate with the physiological and psychological response to that stressor (Sharpe and Curran 2006, Larsen and Hummel 2013, Cohen and Lazarus 1979, Moss-Morris 2013, Tache and Selye 1985, Taylor 1983). The change in situation imposed by the stressor requires adaptation to a new situation. Hence, adaptation involves coping with the stressor by adjusting familiar skills or behaviours *and* developing new routines and automated skills or behaviours that limit the impact the stressor may have on well-being and quality of life. It is a normative process which

everyone goes through when faced with challenges or stressors that interrupt the normal life trajectory in one way or another (Larsen and Hummel 2013, Lazarus and Folkman 1984, Tache and Selye 1985). However, when the stressor originates from one's own body an additional perspective is added to the adaptive process as described by Frank (2013, p. 30):

"People define themselves in terms of their body's varying capacity for control. So long as these capacities are predictable, control as an action problem does not require self-monitoring. But disease itself is a loss of predictability, and it causes further losses [...] Illness is about learning to live with lost control."

Therefore, in the context of chronic illness, adaptation is described as the process and outcome of responding to the stressful events inflicted by the disease and coping with the impact it has on people's lives (Beutel 1985, de Ridder et al. 2008, Larsen and Hummel 2013, Moss-Morris 2013, Sharpe and Curran 2006). These processes and outcomes have been identified as contextual to the nature and extent of the disease and the characteristics and circumstances of the individual (Felton et al. 1984, Stanton et al. 2007, Beutel 1985, de Ridder et al. 2008, Moss-Morris 2013). Adaptation is seen as a dynamic process rather than a fixed outcome evolving over time across multiple life domains as the disease manifests and changes may continue to occur (Moss-Morris 2013, Pollock 1986). The process of adaptation involves the cognitive, emotional and behavioural strategies people develop to promote and maintain their well-being and good quality of life while trying to accommodate the disease in their lives (Beutel 1985, Moss-Morris 2013, Sharpe and Curran 2006). Cognitively, people with chronic conditions have to reconcile their disease within their daily lives and in relation to their self-identity, this cognitive process can be bound with different emotional reactions. They also need to seek information to gain the knowledge to adjust their present lifestyle and acquire the skills to make the behavioural changes needed to deal with their new life situation while enabling them to continue their day-to-day life. The actions they choose to engage in may promote, maintain or impede well-being and good quality of life following their diagnosis (Beutel 1985, de Ridder et al. 2008, Moss-Morris 2013, Stanton et al. 2007).

In this study, the event that instigates the demand for adaptation is the diagnosis of type 1 diabetes in adulthood. When diagnosed with type 1 diabetes, people must develop new skills and behaviours such as insulin injections and blood glucose monitoring to maintain a stable blood glucose level and prevent the hazards associated with diabetes in the short and longer term. They also need to make adjustments in relation to established behaviours such as eating and exercise and, moreover, they must recognise the impact diabetes has on their self-identity, their relationships and their general life situation.

A particular theory on adaptation that has been modelled in the context of diabetes was identified in the literature. Known as the 'Adapting to Diabetes Mellitus' model, this theory was developed by Whittemore and Roy (2002) drawing on pre-existing theories and concepts in nursing (Roy and Andrews 1999, Hernandez 1996, Pollock 1986, Paterson et al. 1999, Price 1993).

'Adapting to diabetes mellitus' a theory by Whittemore and Roy

The 'adapting to diabetes mellitus' theory was developed by Whittemore and Roy (2002) to encompass a holistic person-centred approach to the complexity of living with diabetes. According to Whittemore and Roy, the complexity of diabetes management and the interplay between physiological and psychosocial aspects are key elements in explaining adaptation. In their model they feature the multidimensional nature of diabetes and the different perceptions people might have of the illness. People will respond to the diabetes diagnosis differently depending on their perception of the impact of the diagnosis and their situation in life. Their perception of the impact of the illness will determine to what extent they engage in health-promoting behaviours (self-management). These behaviours are largely connected to stabilising the physical condition and integrating diabetes within their daily life, their relationships and their self-identity. The model suggests that adapting to diabetes mellitus consists of three interrelated continuous processes; stabilisation, integration and health-within-illness. The processes may vary according to the person's life situation and the illness trajectory. It is not regarded as a linear process but ongoing as the person, their life situation, and diabetes change over time. Stabilisation and integration of diabetes in peoples' lives can,

according to the model, lead to health-within-illness, a dynamic process in which the person makes sense of and come to terms with their new life situation.

While the 'adapting to diabetes mellitus' theory was developed from pre-existing theories and does not build on empirical work involving adults with recent onset type 1 diabetes, it may still be useful as a framework for understanding adaptation. However, empirical work is needed to explore the specific phenomena that may influence the adaptive processes immediately following the diagnosis. The 'Adapting to Diabetes Mellitus' theory highlights that adapting to diabetes is a complex process involving multiple dimensions. The model also underscores the interplay between physical stabilisation of the disease and the integration of diabetes into daily life, relationships and self-concept. It describes adapting as an ongoing process that is influenced by the person's perception of the impact of diabetes and their adaptive responses. Therefore, it may be important to explore the complexity of diabetes in more detail and also to understand what phenomena influence the adaptive process from the time of diagnosis. Specifically, it would seem appropriate to further explore the various bio-psycho-social phenomena that are in play and how they affect the early adaptive process. Such an understanding will be important to help provide better supportive interventions to enable a more positive adaptive process and outcome from the time of diagnosis. In the following section the bio-psycho-social model is outlined, as it may add to the understanding of various aspects of adaptation in adult onset type 1 diabetes.

The bio-psycho-social model

To further explore and understand the underlying phenomena involved in the process of adapting to a life with diabetes and recognising the complexity of this process the bio-psycho-social model introduced by Engel (1977) was also used to inform the study's approach. According to this model, equal consideration must be given to the bio-medical aspects and the human experience of living with a chronic condition such as type 1 diabetes. The human experience involves psychological aspects such as the impact on

self and social aspects such as the context in which life with the condition is played out. The bio-medical aspects entail the physical illness and the treatment of it (Engel 1977). In the next section the two core constructs of adaptation and the bio-psycho-social model are integrated to illustrate different aspects of adaptation that could be relevant in understanding the transition to life with type 1 diabetes as an adult. These different aspects of adaptation are outlined to identify how they might be considered within the study.

Adaptation within the bio-psycho-social model

Each individual will have potentially protective and/or detrimental biological, social and psychological characteristics that will influence the impact of the disease and their adaptation to it (Peyrot et al. 1999, Joensen et al. 2013, Joensen et al. 2016, Rassart et al. 2014, Luyckx et al. 2011). The events surrounding the time of diagnosis may also be of significance regarding adaptation, such as the severity of illness experienced and the perceived support people with diabetes receive from those around them (Lawson et al. 2007, Lawson et al. 2008, Lawson et al. 2010). Underlying psychological factors, such as their thinking style and psychological characteristics may also be important determinates of adaptation (Weinger and Lee 2006, Luyckx et al. 2008).

Biological aspects of adaptation

The timeline of the initial biological process preluding the diagnosis of type 1 varies between individuals. For unknown reasons an autoimmune destruction of beta cells in the pancreas leads to a decline in insulin excretion, impacting the body's glucose metabolism to the extent that treatment with exogenous insulin is mandated (Tsai et al. 2006, Atkinson et al. 2014). When insulin treatment is initiated the body will adapt to this new situation and the honeymoon phase will occur. During this phase the beta cells will resume the secretion of insulin to a level where some people can do without exogenous insulin or manage with lower doses of insulin for a period of time (Barker et al. 2014, Oram et al. 2014). However, the beta cell function will continue to decline eventually leading to the need for lifelong exogenous insulin treatment for survival.

Recent studies have indicated that the decline in insulin secretion might be slower than previously anticipated, especially in those with onset of type 1 diabetes after age 18 (Barker et al. 2014, Davis et al. 2015, Oram et al. 2015). In addition, even a small level of insulin secretion following the honeymoon period has been shown to be beneficial in reducing fluctuations in blood glucose values with a possible positive effect on hypoglycaemia, long term metabolic control and complications (Kuhre et al. 2015).

It is well established that diabetes can lead to micro and macro vascular damage in the eyes, the kidneys, the cardio-vascular system, and the autonomic and peripheral nervous system as a consequence of long-term elevated blood glucose (DCCT 2016). Therefore, the aim of insulin treatment is to keep the blood glucose level as close to the normal range as possible without having too many instances of low blood glucose (hypoglycaemia). However, insulin treatment is complicated as the dose needed varies depending on several factors and it requires multiphasic management in relation to both basal and bolus insulin requirements (Thrower and Bingley 2014). While variations in food intake and levels of exercise can be compensated for with insulin therapy, multiple factors come into play meaning this can be a very challenging endeavour. The daily fluctuations of blood glucose demand physiological adaptation on various levels, especially if the fluctuations are wide-ranging or occur within a short timeframe i.e. moving from an incidence of hypoglycaemia to hyperglycaemia within 15 to 30 minutes. Moreover, the short and long term physiological reactions to these fluctuations may be perceived as psychological stress as they can activate the pituitary hypothalamic axis that drives the stress response (Moulton et al. 2015, Lloyd et al. 2005). They can also directly cause negative emotional reactions (fear/anxiety) with a negative effect on well-being and quality of life (Sultan et al. 2008, Grigsby et al. 2002, Karlsen et al. 2004).

Therefore, when considering the physiological aspects of adaptation, it would seem important to recognize their interplay with the psychological aspects by exploring people's perception of the physiological stressors and the ways these impact their overall adaptation to a life with diabetes. It may also be that the physiological effects of the early stages of the disease shape the way the person thinks about and responds to their diabetes, possibly leading to habituated behaviours that may become entrenched in their diabetes self-management practices.

Psychological aspects of adaptation

The studies that have been undertaken of the personal experiences of living with type 1 diabetes suggest that adapting to life with diabetes is critical and challenging. The majority of published studies and previous meta-syntheses exploring the experiences of living with diabetes in adulthood have been with people with longer disease duration or mixed samples of people with type 1 or type 2 diabetes. These analyses suggest that living with diabetes is an ongoing and multidimensional process with a focus on trying to balance their lives with the effects of the disease (Paterson et al. 1999, Nyhlin et al. 1987, Paterson et al. 1998) with key components of this process being: acquiring basic knowledge about diabetes (Campbell et al. 2003, Paterson et al. 1998, Ingadottir and Halldorsdottir 2008, Coates and Boore 1996); developing the necessary self-management skills (Hernandez 1996, Paterson et al. 1998, Ingadottir and Halldorsdottir 2008, Campbell et al. 2003, Price 1993, Wilkinson et al. 2014); gaining supportive relationships with health care professionals (Paterson et al. 1998, Ingadottir and Halldorsdottir 2008, Campbell et al. 2003, Wilkinson et al. 2014, Lawson et al. 2005, Gask et al. 2011, Coates and Ryan 1996); recognising the seriousness of diabetes (Ingadottir and Halldorsdottir 2008, Campbell et al. 2003); and fostering confidence in their ability to manage diabetes (Hernandez 1996, Campbell et al. 2003, Paterson et al. 1998, Paterson et al. 1999, Paterson and Sloan 1994, Ryan and Coates 1998). Other studies show that the process of adapting to diabetes is influenced by underlying psychological factors such as; illness perception (Lawson et al. 2010, Luyckx et al. 2008, Luyckx et al. 2015); and personality traits (Taylor et al. 2003) such as attachment style (Bazzazian and Besharat 2012), resilience (Yi et al. 2008) and coping and thinking styles (Spiess et al. 1994, Duangdao and Roesch 2008, Rane et al. 2011). It is well established that people with chronic illness experience more psychological and social stress than healthy individuals (Royer 1998, Charmaz 1983, Frank 2013). In diabetes this can manifest as diabetes-related distress (Sturt et al. 2015, Pallayova and Taheri 2014, Hilliard et al. 2016, Polonsky et al. 1995, Fisher et al. 2015) or as depression or anxiety (Lustman et al. 2000, Grigsby et al. 2002, Gendelman et al. 2009, Lloyd et al. 2012, Anderson et al. 2001). It has also been recognised that people with diabetes can develop a chronic fear of either complications or hypoglycaemia (Hendricks and Hendricks 1998, Callaghan and

Williams 1994, Anderbro et al. 2010). People exhibiting these negative psychological problems often have poor glycaemic control (Fisher et al. 2010, Schmitt et al. 2014b).

Thus, supporting the person with diabetes early in the diagnostic stages toward better psychological adaptation could be very important in terms of their longer term self-management practices and overall quality of life. A central facet of this may be managing emotions, according to Karlsen et al (2004) emotions and behaviour are in constant interaction with cognitions. The emotional responses related to the diagnosis of grief, shock or anger may cause distress, negative affect or even depression (Reimer et al. 2016, Rane et al. 2011, Spiess et al. 1994) if these feelings are not expressed or taken seriously or acknowledged by others (de Ridder et al. 2008, Stanton et al. 2007, Taylor 1983, Frank 2013). Psychologically the process of adaptation could be characterised by a search for meaning in the experience (Paterson et al. 1999, Taylor 1983, Whitemore and Roy 2002). Therefore, it would be important to explore how various psychological aspects may collectively have an impact on the process of adaptation.

Social aspects of adaptation

A diagnosis of type 1 diabetes has an impact on the person's social context, and conversely their social context may impact how they perceive and respond to the diagnosis (Rane et al. 2011, Royer 1998, Taylor et al. 2003). The level of social support that is available to the individual during the diagnostic phase may shape their adaptation to diabetes such that, while sufficient social support may alleviate their perception of the impact of the diagnosis, a lack of support may intensify their sense of distress leading to tensions that negatively influences their adaptation process (Sharpe and Curran 2006, Frier and Strachan 2017, Stuckey et al. 2014). The influence of social support has been associated with performing self-management behaviours (Joensen et al. 2013, Joensen et al. 2016). In addition to the influence of social factors on adaptation, diabetes also demands some level of adaptation of the social habitus of the individual. Studies in people with longer diabetes duration have described how diabetes may have both negative and positive impacts on personal relationships and family life (Rintala et al.

2013b, Stuckey et al. 2016, Trief et al. 2013, Kovacs Burns et al. 2013). Diabetes not only affects close relationships but might also affect work situations (Ruston et al. 2013, Burda et al. 2012). Some people with diabetes experience stigma related to the disease and may choose not to disclose the disease in work and/or leisure activities which also might negatively impact their engagement in self-management behaviours (Browne et al. 2014, O'Hara et al. 2013, Goffman 1963). Therefore, it would be important both to explore how social support might influence the early process of adapting to a life with diabetes and to consider how diabetes may demand adaptation in their social world.

In summary, the bio-psycho-social model may provide a useful framework for considering multiple aspects of the adaptive process in adult onset type 1 diabetes. While it is possible to consider the elements of this framework as reflected through previous studies, this is the first to use the bio-psycho-social model to explicitly study the adaptive process in adult onset type 1 diabetes in a transnational sample.

To better understand what is already known about the experiences of a diagnosis of type 1 diabetes in adulthood and the following process of adaptation, the next section presents a systematic literature review and meta-synthesis of qualitative studies. The chapter ends with a review of published papers on educational programmes and intervention studies aimed at the adult onset type 1 diabetes population.

Systematic literature review and meta-synthesis

While the insights of the 'adapting to diabetes mellitus' theory, the bio-psycho-social framework, and the previous studies on adaptation in people with longer diabetes duration outlined in the previous sections are useful in elucidating and defining a life with diabetes, they are less useful in helping us understand the needs of people during the formative diagnostic period. Therefore, a systematic literature review and a meta-synthesis were conducted and the aims were:

- to identify studies that explore the experiences of adults in relation to being diagnosed with type 1 diabetes and their adaptation to life with diabetes;
- to synthesise the findings of these studies to identify the underpinning concepts illustrating the early process of adaptation to a life with type 1 diabetes.

Methods

The aim of a meta-synthesis is to translate primary qualitative studies in a related field into each other by combining the parts (the single study) to form a whole (the meta-synthesis) that produces a deeper conceptual knowledge about the field than merely aggregating the findings of each study (Noblit and Hare 1988, Sandelowski et al. 1997, Dixon-Woods et al. 2006, Doyle 2003). The translation provides a deeper understanding of commonalities and divergences in meanings and interpretations across the different studies and encompasses mutual key concepts that might not have been identified in the original studies (Britten et al. 2002, Noblit and Hare 1988, Lee et al. 2015). While meta-syntheses of qualitative studies can be very powerful and informative, they are also technically challenging as there is often inherent heterogeneity between studies in terms of their theoretical underpinnings and methods of data collection and analysis (Thorne et al. 2004). Therefore, it is important to use an open and rigorous approach to enable valid theoretical innovation. To this end we have used an adaptive framework for the analysis based on the methods of meta-synthesis outlined by Noblit and Hare (1988), and Dixon-Woods et al (2006). As outlined, the topic for the meta-synthesis was the experience of diagnosis and adaptation in adults with new onset type 1 diabetes and the synthesis addressed the following questions:

- What are the personal experiences of being diagnosed with type 1 diabetes in adulthood?
- What phenomena influence the process of adaptation to a life with diabetes?

The meta-synthesis was undertaken in three steps as outlined in the following.

Step 1: Search and selection of studies

With the assistance of a librarian, seven databases were chosen for a systematic search of the literature from inception to July 2014. These were: MEDLINE (Medical Literature Analysis and Retrieval System Online), PsycINFO (Psychological Information Database), CINAHL (Cumulative Index to Nursing and Allied Health Literature), BNI (British Nursing Index), ASSIA (Applied Social Sciences Index and Abstracts), Sociological Abstracts, IBBS (International Bibliography of the Social Sciences). MeSH, keywords and free text terminology as appropriate to each database were used to combine general terms focusing on the population of adults with type 1 diabetes (e.g. Diabetes mellitus, type 1 diabetes, insulin-dependent diabetes) and terms relating to experience and adaptation (e.g. perception, adjustment, identity, and related terms). These were used to identify other search terms that might be relevant (Shaw et al. 2004). Both indexed and free text words were used in order to maximize the possibility of retrieving the relevant literature. Also, validated methodological filters for capturing qualitative studies were identified by consulting various guidelines (Flemming and Briggs 2007, University of Texas 2014, McMaster University 2014). Citation and hand searches were conducted from key references and journals to extend study capture. Experts in the field of diabetes and qualitative research were also contacted to identify additional studies and any relevant unpublished work.

Titles and abstracts were screened for relevance according to all of the following inclusion criteria:

- 1) One or more participants had had a diagnosis of type 1 diabetes within five years;
- 2) Participants were aged ≥ 18 years at the time of diagnosis;
- 3) The study explored experiences of diagnosis or adaptation to type 1 diabetes;
- 4) Direct quotations from adults with new onset type 1 diabetes could be identified;
- 5) The study design was qualitative.

The limitation to five years' diabetes duration was chosen to reduce the risk of recall bias regarding their experience of the diagnosis. Full text was obtained for all potentially relevant papers. In cases where it was not possible to determine the age of participants, or the type of or duration of diabetes the original authors were contacted for this information if the paper had been published within five years. Papers were excluded if information was not retrievable or if quotations could not be linked to a specific person with new onset type 1 diabetes.

Step 2: Appraisal of studies

The quality of qualitative studies can be difficult to assess due to a lack of general consensus on criteria for assessment and quality (Sandelowski et al. 1997). The methodological quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP). This tool is a structured approach to appraisal of the technical quality of studies (Sadler et al. 2014), it comprises ten questions related to the design and methodology of the study scoring 0 or 1 for each question to give a total score out of ten (Critical Appraisal Skills Programme 2010). The CASP appraisal score does not in itself direct exclusion of studies unless a specific level of quality is part of the criteria for the meta-synthesis. Excluding studies purely based on methodological quality can be problematic and can lead to relevant material being excluded from the synthesis. Therefore, as recommended by others (Sandelowski et al. 1997, Doyle 2003), studies were not excluded if the source data were adequately reported to enable clear interpretation of meaning.

Step 3: Synthesising the studies

The included studies were read through carefully several times. A data extraction tool was developed to obtain information on: context; research question; objectives; characteristics of the sample; and design and methodology. In a separate table first and second order constructs were extracted following the methods of Britten et al (2002) and Parsons et al (2014). The first order constructs represent the views and experiences of the participants (directly identifiable quotations) and the second order constructs

represent the original authors' interpretations of these views and experiences (expressed as the main themes or key concepts identified in the studies). First order constructs were used to validate second order constructs. If key themes were not supported by identifiable quotes from adults diagnosed with type 1 diabetes within the past five years, the theme was excluded. In the absence of second order constructs these were developed independently from the first order constructs. Third order constructs were derived within and across the studies by comparing and critiquing second order constructs against first order constructs (for examples, see appendix A). Commonalities and divergences across the studies were identified. The third order constructs were further validated by integrating them with the first order constructs (the primary data) from the original studies. The final step of the synthesis was to generate conceptual models integrating the identified constructs expressed in a line of argument synthesis (Noblit and Hare 1988).

Findings

The electronic database search identified 1819 records, leaving 1607 records after removal of duplicates. An additional five records were found through citation seeking. Titles and abstracts of 1612 records were reviewed, and 1536 records were excluded as they did not meet the inclusion criteria. Full-texts of the remaining 76 records were obtained, from which ten records relating to nine studies were included in the meta-synthesis (Audulv 2013, Audulv et al. 2012, Everett 1999, Goldman and Maclean 1998, Johansson et al. 2009, Doktorchik 1991, Samson 2006, O'Hara et al. 2013, Pender 2010, Smith 2010) (see Figure 1 next page).

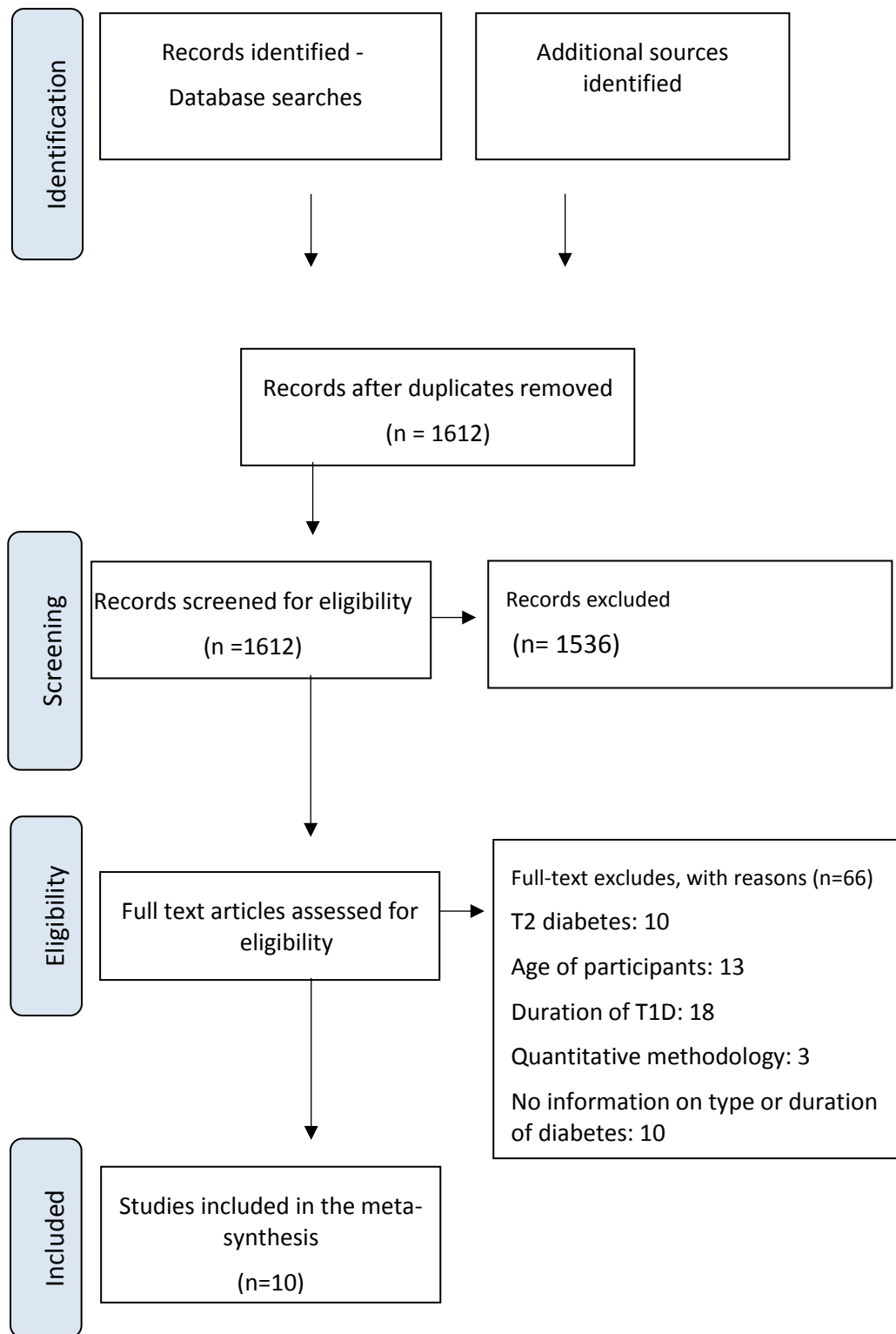


Figure 1 PRISMA flow diagram of excluded and included studies in the meta-synthesis

Overview of included studies

The included studies originated from the UK (n=5), Canada (n=2) and Sweden (n=2). Two papers reported findings from the same study but at different time intervals and both were included (Audulv 2013, Audulv et al. 2012). While three studies exclusively included adults with new onset type 1 diabetes (Everett 1999, Johansson et al. 2009, Pender 2010), four studies included participants with varied duration (Doktorchik 1991, Goldman and Maclean 1998, O'Hara et al. 2013, Samson 2006), and two studies included participants with other chronic diseases (Audulv 2013, Audulv et al. 2012, Smith 2010). The studies were conducted between 1991 and 2013 and involved 124 participants, of whom 17 women and 18 men had been diagnosed with type 1 diabetes within the previous five years. The median age of participants (where reported) was 26.5 years (range 23-58 years). Diabetes duration ranged from four months to five years, with two thirds having lived with type 1 diabetes for three years or less. Ethnic background was rarely stated. Table 1 (on the following page) provides details of the aim, the design and methods of the studies, the number and characteristics of adults diagnosed within five years participating in each study and, in addition, the second order constructs reported.

The CASP scores varied from ten (Audulv et al. 2012, O'Hara et al. 2013, Smith 2010) to three (Everett 1999) with eight studies scoring six or above (Johansson et al. 2009, Doktorchik 1991, Samson 2006, Pender 2010, Goldman and Maclean 1998, Audulv 2013). While the methodological quality of one study (Everett 1999) was poor, it contained a large number of direct quotations from people with new onset type 1 diabetes that could be used in the meta-synthesis.

Table 1 Overview of included studies in the meta-synthesis

Number of participants with recent (≤ 5 years) onset type 1 diabetes (T1D) from each study in the meta-synthesis is underlined

Authors, year, and country	Characteristics of study participants	Aim of study	Type of data collection and analysis	Second order constructs
Study 1 Doktorchik (1991) Canada	2 participants with T1D <u>1 woman</u> <u>T1D ≤ 5 years</u>	To describe the experience of adaptation to diabetes from a personal perspective	Semi-structured interviews Phenomenology	<ul style="list-style-type: none"> • Adjustment • Coping strategies • Control • Normalcy • Social support
Study 2 Goldman and Maclean (1998) Canada	30 participants with T1D <u>3 women</u> <u>T1D ≤ 5 years</u>	To further extend the understanding of individuals' experiences of living with diabetes	Secondary analysis of longitudinal semi-structured interviews Narrative analysis	<ul style="list-style-type: none"> • Confrontation between identity and diabetes • Identity and treatment management

Authors, year, and country	Characteristics of study participants	Aim of study	Type of data collection and analysis	Second order constructs
Study 3 Everett (1999) UK	2 participants with T1D <u>1 woman; 1 man</u> <u>T1D ≤ 5 years</u>	To explore how patients with newly diagnosed type 1 diabetes are coping with the diagnosis and related self-care behaviors	Semi-structured interviews Not stated	Data was presented as first order constructs against established models without developing second order constructs
Study 4 Samson (2006) UK	8 participants with T1D <u>1 woman</u> <u>T1D ≤ 5 years</u>	To explore and describe the experiences of living with type 1 diabetes of people aged 18-25	Semi-structured interviews Interpretive Phenomenological Analysis	<ul style="list-style-type: none"> ● Knowledge
Study 5 Johansson K et al. (2009) Sweden	7 participants with T1D <u>3 women;</u> <u>4 men</u> <u>T1D ≤ 5 years</u>	To develop knowledge from a patient perspective about falling ill with diabetes	Written narratives Phenomenology	<ul style="list-style-type: none"> ● The body in imbalance receives attention of others ● To become a person with diabetes ● The struggle not to become one's disease ● Apparent and uncertain acceptance

Authors, year, and country	Characteristics of study participants	Aim of study	Type of data collection and analysis	Second order constructs
Study 6 Smith (2010) UK	23 participants 17 with T1D 6 with type 2 diabetes <u>2 women</u> <u>T1D ≤ 5 years</u>	To explore how women in midlife perceive the experience of living with diabetes	Semi-structured interviews Journal keeping Interpretive Phenomenological Analysis	<ul style="list-style-type: none"> ● Experiencing stress ● Maintaining Control <ul style="list-style-type: none"> ● Diabetes as a nuisance ● Diabetes in times of crisis ● Diabetes in daily life
Study 7 Pender (2010) UK	16 participants with T1D <u>5 women;</u> <u>9 men</u> <u>T1D ≤ 5 years</u>	To explore the health care experience of adults with newly diagnosed type 1 diabetes mellitus	Focus group interviews (n= 3), individual interviews (n=2) Framework analysis	<ul style="list-style-type: none"> ● Health care experiences ● Emotional responses ● Reactions of significant others ● Strategies to support self-management

Authors, year, and country	Characteristics of study participants	Aim of study	Type of data collection and analysis	Second order constructs
Study 8a+b Audulv et al. (2012) (2013) Sweden	21 participants: Ischemic heart disease (n=4) Rheumatoid disease (n= 5) Irritable bowel disease (n=3) Chronic renal disease (n=3) Multiple sclerosis (n=2) Diabetes (n=4) <u>3 men and 1 woman</u> <u>T1D ≤ 5 years</u>	A: To investigate the integration of self-management into the lives of people living with chronic illness B: To describe the different chronic illness self-management behaviour patterns that individuals develop and maintain over time	Longitudinal in-depth interviews Interpretive description	Study a: <ul style="list-style-type: none"> ● Negotiating self-management that fits into life ● Costs and benefits of self-management ● Creating routines and plans of action ● The influence of an Individual's context on self-management integration <ul style="list-style-type: none"> • Life situation • Personal beliefs • Social support Study b: <ul style="list-style-type: none"> ● Consistent versus episodic self-management pattern ● On demand self-management pattern ● Transitional self-management process ● On demand versus transitional self-management

Authors, year, and country	Characteristics of study participants	Aim of study	Type of data collection and analysis	Second order constructs
Study 9 O'Hara et al. (2013) UK	15 participants with T1D <u>1 man T1D ≤ 5 years</u>	To gain an understanding of what life is like for men with type 1 diabetes	Semi-structured interviews Grounded theory	<ul style="list-style-type: none"> ● Reducing the seriousness of diabetes ● Reaching goals and mis/managing illness

The synthesis

The analysis of the first and second order constructs followed by a translation of the studies into each other revealed six third order constructs; these were: disruption; constructing a personal view of diabetes; reconstructing a view of self; diabetes impact on life context; learning to live with diabetes; and behavioural adaptations. These constructs are presented below supported by first order constructs from the original studies in italics. Appendix A shows examples of the integration between the first and second order constructs from the original studies.

Disruption

Disruption was a third order construct that reflected the impact diabetes had on people's lives. The diagnosis of type 1 diabetes was perceived as disrupting their life trajectories and aspirations for the future. As type 1 diabetes is a fairly rare condition most people did not have any prior experience of how the condition could impact daily life. Adults with new onset type 1 diabetes expressed their experience of disruption in relation to the physical, psychological, and social aspects of their lives.

Physical disruption

The initial experience of diabetes typically involves various physical symptoms leading to the diagnosis. These symptoms were often insidious and confusing for the individual, leading to feelings of uncertainty as to what was happening to them (Pender 2010, Johansson et al. 2009, Smith 2010). Some people resisted acknowledging their symptoms (Pender 2010) and tried to minimize or explain away the symptoms: *"I thought I had come down with the stomach influenza"* (Johansson et al. 2009). Others experienced symptoms that were more severe and viewed the diagnosis as positive, at least initially (Everett 1999, Johansson et al. 2009, Pender 2010, Smith 2010), as the commencement of insulin reduced their symptoms: *"The immediate effect after the first syringe was that I did not have to rush to a toilet... nor did I have to pee as often as before"* (Johansson et al. 2009). In addition, people's prior view of their body also affected their response to the diagnosis:

“When I went to the hospital they take me inside, checking blood, and they tell me that I am diabetic type 1, and I was surprised really, I did not expect that, my body is not like a diabetic person” (Pender 2010). Others resisted acknowledging their symptoms and had difficulty understanding what was happening in relation to their health: *“The occupational health nurse began by asking if I felt well and I naturally answered yes, because I wanted to feel well. So somewhere I understood that something was not right, but I did not understand what”* (Johansson et al. 2009).

Psychological disruption

Receiving information on the diagnosis was generally perceived as a shocking experience (Johansson et al. 2009, Pender 2010, Smith 2010) requiring immediate adaptations in the person’s outlook on past and future possibilities and roles *“I was the strong one in the family. And suddenly I’m this diabetic, and it’s really hard to accept that you’re not as healthy as you thought you were. I’d always thought I was very lucky, and I never felt restricted about anything”* (Goldman and Maclean 1998).

The diagnosis often provoked emotional reactions (Goldman and Maclean 1998, Johansson et al. 2009), for example, one participant said: *“I was very angry and cross when I came to the hospital”* (Everett 1999), although for some there was a sense of denial: *“I felt like saying, ‘How do you know?’”* (Everett 1999). The impact of the diagnosis was something of a shock for the individual: *“Overnight everything changed”* (Johansson et al. 2009) and they needed time to process their diagnosis (Doktorchik 1991, Johansson et al. 2009, Pender 2010). This emotional response was influenced by the way the diagnosis was communicated, and the support provided:

“And she gave me this letter and told me to go to A&E and it was there that I realised because and there was a room full of people and I jumped the queue and with people with broken arms and everything. I realised then it was probably quite serious, more serious than I thought. And then, yep, I got a real bounce after it” (Pender 2010).

The psychological response to diagnosis was also reflected in the way people perceived their new life situation as something having a profound impact on their lives, with the realisation that diabetes does not go away and is a lifelong condition (Doktorchik 1991,

Everett 1999, Goldman and Maclean 1998, Johansson et al. 2009). This was expressed in feelings of loss and grief for the possibilities and flexibility of their previous life: *"After the initial diagnosis sinks in there is the pain of accepting the loss of your good health. Alongside this is the 'neverendingness' of it – that's when I think you need some emotional support"* (Smith 2010).

Social disruption

Social disruptions in terms of relationships and in the context of work and life in general were also reported by adults following their transition into diabetes (O'Hara et al. 2013, Pender 2010, Johansson et al. 2009, Audulv 2013, Goldman and Maclean 1998, Smith 2010). They reported changes in their relationship structures, with family and friends becoming more concerned with the person's health and well-being rather than with their more regular interactional issues. Some participants also found it difficult to relate to the emotional reactions of others: *"People are crying and I am saying I'm fine. Those two people are the only two people who treated me, essentially how I should have been treated. And get on with it. And everyone else is falling over themselves to help. Very strange that part of it"* (Pender 2010).

This could also affect how they perceived the support offered by friends and family and again disrupted social interactions: *"People stopped asking what you did at work or if you had fun when you last met your mates and instead only asked how you felt and what the blood sugar readings were"* (Johansson et al. 2009).

Another form of social disruption was the negative impact the disease had on their present employment (Smith 2010, Pender 2010). One person explained: *"I have lost as well my job"* and also on future work opportunities: *"They revoked my [driver's] licence and [at] that time I became jobless"* (Pender 2010).

Constructing a personal view of diabetes

Following the initial responses to their diagnosis, people then had to adapt to a life with diabetes. An important construct that may influence this adaptation was the way the person perceived diabetes and the extent to which they associated or dissociated diabetes

within their life context. These perceptions were expressed in the following third order sub-constructs:

Perception of diabetes

The way that individuals adapted to life with diabetes was influenced by their view of the seriousness of diabetes and its impact on their health and life in general. These perceptions varied between individuals. Some people tended to minimize the significance of the disease to reduce the impact it had on their everyday life: *"It's not really that bad, it's just annoying the time it takes"* (O'Hara et al. 2013). Others perceived the prospect of long term consequences of living with diabetes as more serious with the potential to damage their bodies in the future (Audulv 2013, Audulv et al. 2012, Goldman and Maclean 1998, Johansson et al. 2009, Pender 2010, Smith 2010). This perception of diabetes could be related to more activated engagement in self-management for some: *"If you want to feel well, you have to manage it so that it does not damage the body, for you have to live with that for the rest of your life"* (Johansson et al. 2009). Others were conscious of how diabetes could potentially affect their relationships:

"I think, you know you can be a victim, you can enjoy that kind of 'oh everyone will feel sorry for me now because I've got that or whatever you've got' and really make a meal of it 'Oh no we can't do that because I've got diabetes, so we'll have to do this because ... ' I don't like to, I mean I will, if I really have to I will, but you know I don't want to, I'm not really a victim anyway. I think that's a kind of personality that you can have, but maybe I just identify with that because I could be like that so I don't want to be like that, so "" or even a martyr to it really, You know, it can fill a role in your life, you know, you could start manipulating everybody with it" (Smith 2010).

Association and dissociation

Individual perspectives on diabetes were quite divergent in terms of whether they associated or dissociated the disease with themselves. Some people seemed to develop a strong and sometimes overwhelming association between themselves and the disease (Everett 1999, Goldman and Maclean 1998, Johansson et al. 2009), viewing the diabetes

as something that had taken over their sense of self: “[*Thoughts about my diabetes*] take up seventy-five percent of my time awake each day” (Audulv et al. 2012). Such a response could lead to a preoccupation with diabetes and that it enforced restrictions on their lives: “*I have to eat at set times. Diabetes dominates my routine*” (Everett 1999).

Other people dissociated their sense of self from their diabetes and viewed the diabetes as something that was outside of them to help limit the impact the disease had on their day-to-day life: “*Apart from the injections, diabetes has not made any great differences. It's fine. It's something I can easily live with*” (Everett 1999).

In other circumstances this disassociated orientation manifested as a more *laissez faire* approach to diabetes and self-management (Audulv 2013, Audulv et al. 2012) which also impacted communication about the illness: “*That I have come down with diabetes is something I actually do not think of very much and I do not like talking about it either. I can compare it to having a weird neighbour. You cannot get rid of him and you do not want to talk to or about him so you just have to relax and go on living*” (Johansson et al. 2009). Viewing diabetes in this way could lead to a level of disengagement with practices such as attending to food and blood glucose monitoring:

“*I feel like there are so many other things going on in my life I just don't have the time, energy, or interest to monitor it as closely as I did when I first was diagnosed and was really frightened. It takes time and it takes interest, and it's sort of fifteenth on your list of priorities. There are so many other things in my life and it always seems to me that ever since I can remember I don't have enough time to do all the things I wanna do. And, the thing that's the easiest to let go is your own exercise or whatever, so you can accomplish these other things*” (Goldman and Maclean 1998).

Reconstructing a view of self

This construct expressed an aspect of psychological adaptation to diabetes in terms of how the individual reconstructed their sense of self following a diagnosis of diabetes. For many adults the diagnosis seemed to lead to significant changes in personal identity, their position in the world, the way they engaged with others and their future aspirations and goals. How they reconstructed their sense of self could be related to past experiences and,

as detailed in the previous construct, their perceptions of the disease. Therefore, the way adults adapted to diabetes and reconstructed their sense of self seemed to vary between individuals.

Diabetes and self-identity

Some people found it difficult and demanding to relate to the changes imposed by being diagnosed with a chronic condition and how this had an impact on their self-identity (Everett 1999, Johansson et al. 2009, Pender 2010, Smith 2010). While some actively resisted the impact diabetes might have on their self-identity: *"I can't be somebody else and I'm certainly not going to be somebody else because of this condition"* (Smith 2010), others had a different perception. The initiation of treatment was a sign that they were no longer the same as before, as they began to reconstruct themselves as a person with diabetes: *"Your whole opinion of yourself changes, everything changes. It's not just physically; mentally it really kind 'a throws you off. Like I don't think I lost self-confidence but it just changed my way of thinking. Like I'm not what I thought I was"* (Goldman and Maclean 1998). For some people this could lead them to reject their treatment in order to reduce the impact of diabetes on their identity: *"I thought that if I ate less and took less insulin; I was much less a diabetic"* (Doktorchik 1991).

For some the consequences of having to redefine themselves as a person with diabetes had a negative effect on their mood, causing feelings of anger and resentment (Everett 1999, Goldman and Maclean 1998, Johansson et al. 2009, Smith 2010). They felt their personal behaviours were altered by diabetes, which had a negative impact on their interactions in the social world possibly leading to social isolation:

"Now it has passed so long [time], at the beginning it was so clear regarding how much you changed your lifestyle. Now it is more like... now you begin to be more used to it, [you] are a little more withdrawn. Your mood is affected also, you are going to do something and you can't do everything, then it's not as fun anymore. You go to the pub and can't follow the guys in the way that you would want to (...) then it's just to go home" (Audulv 2013).

While for others the diabetes diagnosis did not have such a major impact on their sense of self or personal identity (Goldman and Maclean 1998, Johansson et al. 2009). This type of response seemed to be related to their perception of diabetes: *“Diabetes is just something unfortunate that has happened. I don’t feel any less of a person because of it, I just get on with it”* (Everett 1999).

Views of others

An additional factor in reconstructing their self-view was how others responded to them as a person with diabetes. While the person’s own sense of self may not have been altered they found that others viewed them differently (Pender 2010). This could lead to conflict as the person with diabetes felt they were the same person as before and yet other people treated them differently (Audulv 2013, Johansson et al. 2009, Goldman and Maclean 1998, Smith 2010).

The diabetes dilemma

In adapting to a life with diabetes some people struggled to find a balance between spending all their time on their diabetes to become the perfect person with diabetes (Everett 1999, Johansson et al. 2009, Smith 2010) and spending too little time on their self-management: *“How sloppy can you be before you’re too sloppy and how proper can you be before you’re too proper?”* (Audulv et al. 2012). This dilemma could influence their perception of their ability to engage with the demands of diabetes. The conflict between attending to behaviours related to diabetes and the struggle to accept the disease could lead people to assess themselves negatively:

“I don’t think I’ll ever be under really excellent control. So I don’t know if I’m ever going to feel good about myself, or if I’m just finally going to accept the way things are and not let it bother me. I hope I come to it soon. I’m just getting fed up, I know that you have to feel good about yourself and all that, but I’m not happy with myself” (Goldman and Maclean 1998).

For some this negative perception of self was reinforced when they made choices inconsistent with recommended diabetes self-management and could lead to a

judgemental attitude towards their own behaviours: *"I feel like a very bad diabetic person when I buy an American pizza"* (Audulv et al. 2012).

Diabetes' impact on life context

The diabetes diagnosis affected the structure and schedule of their social life, challenging the person to find a place for diabetes in their life. During the early phases of life with diabetes some people reported significant adaptations in routine social behaviours. These adaptations seemed to be related in part to experiential learning as people with diabetes discovered certain limitations that diabetes might impose on their behaviours and relationships.

Stigma

Stigma could have a strong effect on social adaptation with individuals adopting restrictive behavioural adaptations in response to the stigmatising effect of diabetes: *"It is not the fact that I have to take shots, that is particularly hard, but that people have to treat you in a special way because you take shots that is the hardest. That I am not a different person and that I am neither kinder nor more stupid and strange just because I fell ill"* (Johansson et al. 2009).

One example of how the stigmatisation was actioned was the way others felt at liberty to impose rules and judgements on them: *"You're a diabetic, you can't eat this"* (Pender 2010). For the person with diabetes such judgements tended to reduce their sense of personal autonomy (Audulv et al. 2012, Goldman and Maclean 1998, Pender 2010). Another example of how misperceptions and lack of knowledge about type 1 diabetes could affect social interactions was in relation to experiencing an episode of hypoglycaemia in public: *"Strange night - last night. Went to jazz concert to see friend's band. I felt 'strange' during the performance and my friend 'dealt' with me. When I recovered- a woman from the audience came over and complained about the noise from our table. I think it's the first time I have felt discriminated against"* (Smith 2010).

Life structure

Pre-existing social structures and commitments could influence the way individuals adapted to diabetes. While for some the structure of life and work was perceived as providing a context for positive adaptation to diabetes (Audulv 2013, Audulv et al. 2012, Johansson et al. 2009); for others work might put some restrictions on adaptive behaviours (O'Hara et al. 2013, Smith 2010). Some would privilege the demands of work over diabetes-related behaviours: *"Because if you are working you have to wash your hands, it's filthy. It's working on the walls, its freezing over there. On the job there's nowhere to wash your hands. It's all right now. Definitely not testing as much"* (O'Hara et al. 2013). The daily structure supported by having a job and being in a close relationship was for some perceived as a help in managing their diabetes:

"I think it depends a lot on that, during the summer, I lived a relatively normal life for the first time. My girlfriend and I lived together, and we had our jobs and we came home in the evenings... Then [the diabetes] was a minor problem, it was managed... Now [being unemployed], I have no regular lunch time, no regular coffee breaks. I get up at different times. It becomes much harder. Everything is harder in a way. When it is harder, you spend more time thinking about it, then it [diabetes management] is not that automatic" (Audulv et al. 2012).

The influence of significant others

The way individuals adapted to diabetes also seemed to be influenced by their relationships with significant others. While for some these relationships supported adaptation (Doktorchik 1991, Goldman and Maclean 1998, Johansson et al. 2009), others experienced limited support or interactions that could be perceived as antagonistic to the adaptive process (Everett 1999, Smith 2010). The limitations imposed by diabetes could be challenging for family members and potentially affected their ability to provide support to the person with diabetes. *"My husband finds diabetes intrusive, e.g. I don't like my evening meal to be too late now. It wouldn't worry him if we went to the pictures and then didn't eat until 10.30 but I can't do that"* (Everett 1999).

When family members attempted to show support by asking about their diabetes it was sometimes perceived as unhelpful: “My parents can never talk to me about anything other than how I feel, when I spend my whole breakfast and my whole lunch, my whole dinner talking about how my diabetes [management] is going” (Audulv et al. 2012).

Learning to live with diabetes

This construct reflected the learning that adults diagnosed with type 1 diabetes experienced as they made the multiple adaptations required to live with diabetes. The person’s learning was multileveled and interacted with other thematic areas related to how they perceived diabetes and their reconstructed view of self and the impact on life context. The psychological adaptation to the disease could influence how the person learned to live with the disease. Learning encompassed both the adoption of health-related behaviours and practices that could be perceived as positive and negative. It could also be influenced by interactions with others including health care professionals and services. These interactions are expressed in the following sections.

Learning to learn

It would seem that part of the learning process for patients was understanding the need for themselves to learn and to develop strategies to help them learn from their experiences (Audulv 2013, Audulv et al. 2012, Doktorchik 1991, Everett 1999, Goldman and Maclean 1998, Johansson et al. 2009, O’Hara et al. 2013, Pender 2010, Samson 2006, Smith 2010). This understanding very much depended on their level of acceptance of the disease (Doktorchik 1991, Goldman and Maclean 1998, Johansson et al. 2009, Smith 2010). In particular, they needed to be able to process all the information and self-management processes involved in adaptation to diabetes. It also suggested that at diagnosis giving patients too much information could be overwhelming and inhibit learning: “I don’t think when I was first diagnosed I took it all in, you know, in one ear and half of it going out the other just simply because I was overwhelmed by it – takes time to sieve through it and process it” (Pender 2010).

Further obstacles to productive learning could be related to people's underlying psychological adaptation and acceptance of the disease: *"But then it was a case of I probably didn't learn about, learn a lot about it just because I didn't want to"* (Samson 2006).

For some seeking additional information outside the health care system was a way to learn more about diabetes. While for others additional information given out of a health care context was not conducive for learning: *"I went on the internet a lot which I think is a really bad idea. Really old mostly American web sites about how you are going to go blind and lose your hands and feet. So I wouldn't recommend random googling especially in the middle of the night. Reading about going blind [is] really bad"* (Pender 2010).

Learning support

An important aspect of learning from the person's view was the support they received from others, generally health care professionals (Audulv 2013, Audulv et al. 2012, Doktorchik 1991, Goldman and Maclean 1998, Johansson et al. 2009, Pender 2010, Samson 2006). People with type 1 diabetes had different experiences of support. For some learning was supported and encouraged by health care professionals with a positive impact on how they adapted to diabetes. Preferences for the way supportive information was provided also varied, with some wanting choices over what they were told: *"My GP was all for me to learn to adjust my own insulin. This made a big difference in how I view diabetes... It would have been harder to accept if he tried to tell me everything I should be doing"* (Doktorchik 1991); while others preferred clearer guidelines: *"What I could and can't eat; clearer guidelines on that"* (Pender 2010).

For others the information provided by health care professionals was not sufficient for living with diabetes in the context of everyday life (Everett 1999, Goldman and Maclean 1998, Pender 2010). Some expressed a need to learn from other people with type 1 diabetes who actually knew what it was like to live with diabetes:

"[Talking to others with type 1 diabetes] could have helped, it would have certainly given me a bigger picture kind of thing. And they could teach me anything to do with my day to day diabetes. They could have certainly told me, you know what I mean, the wider picture

of dealing with diabetes which I always felt was quite weird with the doctors and nurses telling you about something, and it is one of those things you have to go off and do by yourself, and yet they don't – you know what I mean” (Pender 2010).

Learning through experience

Experiential learning was identified as a key learning strategy, trying out different self-management strategies was part of people’s adaptation. Even if the experiment turned out not to work, it still enabled them to make further adaptations to their practices (Audulv 2013, Audulv et al. 2012, Doktorchik 1991, Everett 1999, Goldman and Maclean 1998, Johansson et al. 2009, O’Hara et al. 2013, Pender 2010, Samson 2006, Smith 2010). For example, one study participant explained *“I have made mistakes by giving too much insulin and gone from high to low and I have also given too little and my blood sugar has been 16 or 19, but you have to go through these experiences to learn” (Everett 1999).*

Others reported using personal experiments to test the limitations of their disease: *“And most of all [I was] curious, so I tried and did not take insulin for two days or something. At first, nothing happened; it [the blood glucose level] remained, so to speak, until I saw that one day I got a higher level, and then I understood that I should not experiment on my own anymore” (Audulv et al. 2012).* This process of self-experimentation seemed to be important in shaping how people adapted to diabetes (Audulv 2013, Audulv et al. 2012, Doktorchik 1991, Everett 1999, Pender 2010, Samson 2006, Smith 2010). They learned through time the parameters of the disease and how their behaviours had an impact on it: *“I would eat half of what I would normally eat thinking oh god too much sugar or something not realising that I could eat things like that. It was one of those; it took me quite a while, ages” (Pender 2010).*

The learning flux

Diabetes was perceived as a dynamic condition requiring constant change and adaptation. This was particularly true in the early stages of the disease. Learning needs were continually changing within the context of different stages of the disease (Goldman and Maclean 1998, Johansson et al. 2009, Samson 2006, Pender 2010, Smith 2010). Initially

some people found it daunting to learn about potential impacts diabetes may have on their life situation: *“You painted horror scenarios, that I would never more be allowed to eat junk food, sweets or drink lemonade, but instead only have to eat beans and broccoli. Of course it does not work that way. I allow myself sweets sometimes, but in general I have stopped which is essentially good”* (Johansson et al. 2009). While people felt the change, diabetes had imposed on their present situation, there was an awareness that additional adaptations would have to be made in the future in case they encountered complications:

“[Diabetes is] another thing to put into an already hectic life with enough choices, then to throw this one in, because the weight of this one is not only for now, what it does to me now, it's the effect of what's it going to do when I'm 60, 70, 80? Is it going to be my eyes that go, is it going to be my feet, is it...? You know I've just met a colleague of my husband's who's just had his leg off through diabetes. When you hear things like that you feel 'God I'm totally responsible for the next 20 years of my own health'” (Smith 2010).

Understanding when to seek more information and knowledge regarding the changes that occurred in the early phases of the disease could be challenging (Goldman and Maclean 1998, Johansson et al. 2009, Pender 2010). If changes occurred ahead of the person's understanding of the disease and without appropriate learning support, it could result in them reflecting negatively on their own ability to manage the disease. Signposting specific events in the trajectory of diabetes could be conducive to seeking help at appropriate times. The honeymoon period, when the patient may have some residual endogenous insulin, was a particular phenomenon in the learning flux, in that when the patient thought they had made adjustments to the disease, the honeymoon was over and new learning was required: *“You could have a whole file on everything and a caveat saying – honeymoon comes first”* (Pender 2010).

Behavioural adaptation

Adults diagnosed with type 1 diabetes needed to make a range of changes to their established behaviours, as well as adopting new behaviours. There were major differences in how people adapted their behaviours, suggesting an interaction with the previously identified psychological adaptations, their perception of diabetes, the way they reconstructed diabetes in relation to their self-identity and their approach to learning.

People used a range of strategies to adapt their behaviours. Some individuals preferred more flexible strategies regarding their self-management behaviours, while others adopted more rigid methods. In the data there were examples of how being flexible could be a positive adaptation, enabling the individual to choose from different behaviours in response to changing circumstances (Doktorchik 1991, Goldman and Maclean 1998, Samson 2006, Smith 2010). People who adopted more flexible strategies also seemed more orientated to use experiential learning in adapting to diabetes. They also applied flexibility in terms of their level of attention to behaviours (Audulv 2013, Goldman and Maclean 1998). For example, they would choose to do blood glucose testing more or less intensively: *“At the moment I am experimenting with eating different foods, so I want to know how that is affecting me so I am testing four times a day”* (Everett 1999).

There were other individuals who preferred more rigid strategies regarding management of their diabetes which could be reflected in their behavioural adaptations. While there was some sense of control (Audulv et al. 2012, Everett 1999, Johansson et al. 2009, Smith 2010) and security for them in following this strategy it could also impose restrictions on their lives: *“It is a nuisance when you are out for the day and you have to stop at the right time. I always have to test my blood if I am shopping or walking to make sure it is level”* (Everett 1999). This less flexible model could also be challenging when the pattern of the day was disrupted or the context changed, such as during holidays. Again, this could be restrictive as the person may avoid situations or contexts where they could not apply their rigid model. Limited knowledge could be one reason for choosing this strategy: *“There are some problems with having diabetes. You have to have regular mealtimes and you cannot be sloppy about it (...) So it becomes a problem when you are away at a party, when perhaps it goes a little bit longer between meals”* (Johansson et al. 2009).

Conceptual models

As highlighted, the third order constructs identified seem to be interactive. When viewed collectively it is possible to consider how these phenomena inform the processes of adaptation in an adult diagnosed with type 1 diabetes. Figure 2 (on page 50) proposes a model to capture these potential interactions and express them as a process of adaptation within their social world.

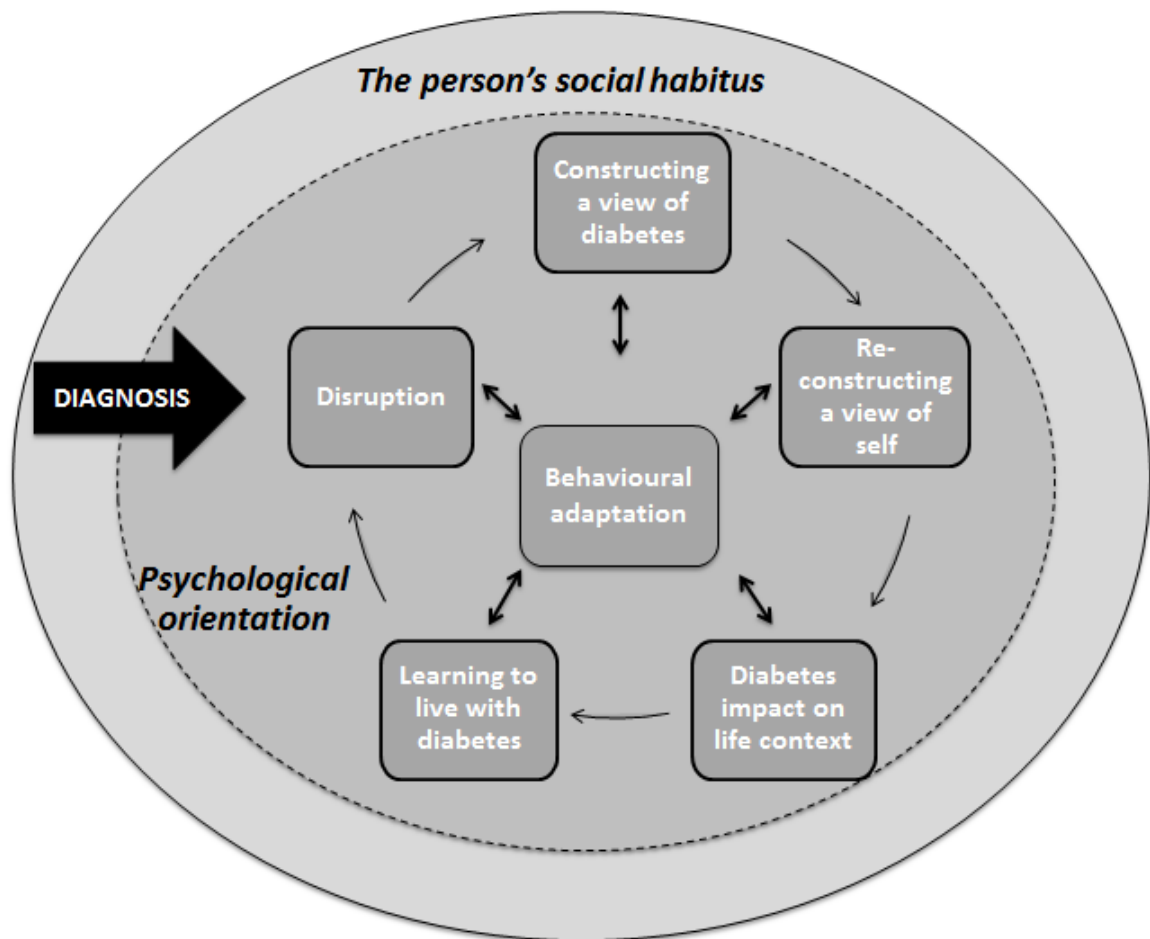


Figure 2 The interrelated processes of adaptation in adults with new onset type 1 diabetes

The model suggests that the diagnosis initiates a disruption to habitual life. The person's response to the disruption requires that they need to construct a view of diabetes and reconcile this with their own self-identity. This process is likely driven by their underlying psychological orientation and thinking styles together with their interactions with others. The model further illustrates how the person must also address their diabetes within their life context, which may necessitate significant changes in personal relations and their social habitus. To do this they must develop strategies to enable them to live as a person with diabetes. This involves learning about themselves, the condition and their experiences in the social world. This learning is influenced by the support they receive and their experiences of living with diabetes. These adaptive processes may have a significant impact on the person's behavioural adaptation at the centre of the model. It has been clear from the synthesis that there is variation within these adaptive processes. This

variation is illustrated in Figure 3 (on page 52), which tries to capture some of the continua expressed within the different constructs within the process of adaptation. This model details the different styles of adaptation people identified. These styles may have both positive or negative impacts on the adaptive process and ultimately their self-management behaviours and whether or not they develop diabetes complications.

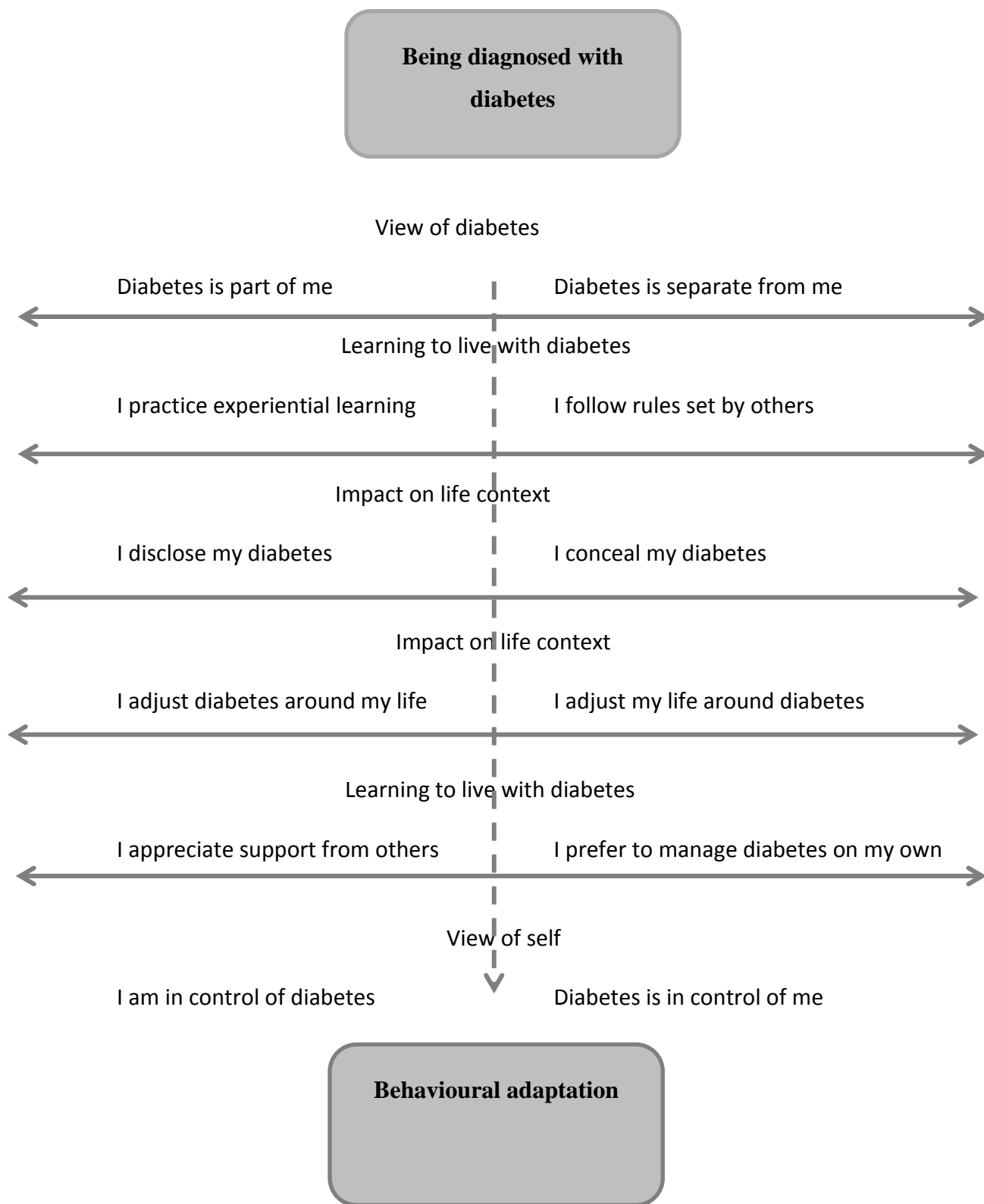


Figure 3 Adaptive thinking styles in constructing an identity as a person with diabetes

Discussion

The synthesis has provided new insights into the early process of adaptation that occurs following a diagnosis of type 1 diabetes in adults. From the data it is evident that the diagnosis has an immediate disrupting impact on physical, psychological, and social aspects of life. This finding is resonant with Bury's (1982) work, which described the emergence of chronic illness as a biographical disruption (Bury 1982). The present study extends this interpretation by suggesting interplay between the physical changes that occur to the body and the psychological and social stress it brings to bear on the individual. This disruption demands a process of adaptation and can trigger psychological distress. This early adaptive phase may have longer-term consequences as beliefs and behaviours related to diabetes are formed. Hence, early supportive intervention might address the person's distress and perhaps help shape more positive adaptive thinking styles and behaviours.

The synthesis shows that the process of adaptation may be linked to how people construct a view of diabetes. While previous studies have highlighted different dimensions of the process of adapting to diabetes (Campbell et al. 2003, Hernandez 1996, Ingadottir and Halldorsdottir 2008, Paterson et al. 1999, Paterson et al. 1998, Maclean 1991), the synthesis suggests that constructing a view of diabetes interrelated with self-identity are important aspects of adaptation. It was also observed that this formation of diabetes and self-identity seems to shape adaptive strategies and behaviours early on. The way an individual constructs diabetes was often expressed in terms of a conflict between their life in general and the demands of the disease. While this conflict has been identified in other studies of adults with longer durations of diabetes (Ingadottir and Halldorsdottir 2008, Paterson et al. 1999, Campbell et al. 2003, Zoffmann and Kirkevold 2005, Smith 2010), the study observations suggest that it takes root early on in the disease's course and can impact self-management behaviours and hence long-term outcomes. The synthesis has identified the diabetes dilemma, the conflict between the sense of self and the idealised view of a person with diabetes. The notion of being the 'perfect diabetic' person and being able to live a normal life might seem irreconcilable for many, leading to negative self-assessment and a lack of confidence in their ability to manage diabetes.

While other studies have identified this conflict in people with longer diabetes duration (Karlsen and Bru 2002, Campbell et al. 2003, Ingadottir and Halldorsdottir 2008, Wilkinson et al. 2014, Ryan and Coates 1998) we see here that it takes root early in the disease trajectory. Such perceptions may be unwittingly reinforced by health care professionals by setting unrealistic goals for people with type 1 diabetes – a practice that may also have a negative impact on the relationship between the person with diabetes and the health care professionals (Snow et al. 2014, Maclean 1991, Zoffmann and Kirkevold 2005, Wilkinson et al. 2014). Therefore, providing adequate support to people at the time of diagnosis to foster more positive and realistic perspectives on themselves and a life with diabetes may reduce the often-identified negative self-perceptions, unhelpful behavioural responses and diabetes distress (Pallayova and Taheri 2014, Berry et al. 2015, Fisher et al. 2014, Fisher et al. 2015, Hartrick 1998, Knight et al. 2006, Coates and Ryan 1996).

In contrast to children, adults have to adapt to diabetes in the context of a life already well established in the social world. Grief and mourning over the loss of their well-known lives was evident in the accounts of participants in the reviewed studies. This sense of grief is not unique to diabetes; it has also been reported in relation to other diseases (Charmaz 1983, Taylor 1983, de Ridder et al. 2008, Frank 2013). It has been observed that feelings of anger and resentment towards the disease can affect the ways in which people come to terms with their loss and their adaptation to the disease (Campbell et al. 2003, Ambrosio et al. 2015, Brown 1985). The responses of the social world to them both in terms of their relationships, and in terms of employment and their economic well-being were also seen to be influential. Diabetes can be stigmatising with the person being constrained during interactions with others because of their diabetes, which can be frustrating for the individual (Browne et al. 2014, Goffman 1963). Therefore, recognition of their lost life and the development of strategies to deal with and anticipate the social effects associated with diabetes could again encourage positive adaptation.

Accepting diabetes has been associated with the ability to balance the demands of diabetes with living a 'normal' life (Paterson et al. 1998, Hernandez 1996, Campbell et al.

2003). However, accepting diabetes and finding this balance may be challenging for many (Ambrosio et al. 2015, Richardson et al. 2001, Lo and MacLean 2001, Nyhlin et al. 1987). A key influencing factor may be the way an individual learns to deal with their diabetes. The synthesis shows that this learning can take many forms such as information-seeking behaviours and experiential learning strategies. This learning begins from the moment of diagnosis and without some supportive guidance may lead to the development of unhelpful adaptive behaviours and thoughts (Maclean 1991, Karlsen and Bru 2002, Wilkinson et al. 2014, Morris et al. 2006, Taylor et al. 2003). In some cases unsupported learning activities may lead to risk taking behaviours and fixed ideas that could become an impediment to future learning (Celano et al. 2013, Colagiuri and Eigenmann 2009). Again, this indicates the need for early intervention to introduce positive learning styles and appropriate information support.

Finally, the theoretical models identified in the study emphasise and illustrate the interactivity between the identified constructs. The models introduce a more dynamic expression of the findings within the collected studies. These models may help inform the development of early stage supportive interventions. The key message would seem to be that behavioural adaptation begins early and is shaped by emotional reactions to the disease, the person's view of diabetes and its impact on their sense of self and the influence of the social world. While clearly adaptation will be influenced by prior personality traits and thinking styles, there may be a window of opportunity to shape some of the adaptive processes through interventions that reflect the psychosocial phenomena of that process. In so doing, consideration should be given to: the emotional response to the diagnosis; the development of informed experiential learning and self-reflection; the promotion of positive personal and social coping strategies; and perhaps most importantly enhancing their self-worth. This may also require a degree of normalisation of their experiences such that they do not feel isolated.

There are some limitations to the meta-synthesis. The trustworthiness of the findings of a meta-synthesis is restricted to the quality of the primary studies (Britten et al. 2002). The meta-synthesis did not exclude any studies on the basis of quality and while most had

adequate quality some were at a lower level. However, all the studies contained enough primary data to be able to develop constructs even when the studies were of a poorer quality. Another inherent issue in meta-synthesis is the issue of methodological heterogeneity (Sandelowski et al. 1997), which was evident to some extent in this review although most followed similar analytical models. It has also been contended that this heterogeneity is beneficial as it extends the range of views analysed (Pope et al. 2007). Although there was heterogeneity in methods there was to some extent homogeneity in the samples as all studies were conducted in westernised societies with easy access to health care. This may limit the transferability of the findings to less affluent countries and countries with less access to health care; however, the psychological impact of a diagnosis might to some extent be universal. A further potential challenge to the analysis was that some studies had participants with longer disease duration and two studies included participants with other chronic conditions. However, it was possible to bracket the analysis to adults diagnosed within the past five years by cross checking first order construct sources to validate third order constructs.

Conclusions

The meta-synthesis has provided an understanding of the adaptive processes that follow a diagnosis of type 1 diabetes in adulthood. The findings indicate that there are differences in these adaptive processes between individuals and these can shape long-term behavioural patterns and psychological distress. Having expressed the interrelated phenomena associated with that process, the synthesis reveals some important potential areas for supportive intervention to enhance the adaptive models adopted by adults when diagnosed with type 1 diabetes. However, the included studies that were conducted specifically on the adult onset population focused more on different aspects of people's experiences rather than on exploring the process of adaptation. Two were small in size (two and seven participants, respectively) (Johansson et al. 2009, Everett 1999) and mainly included people diagnosed within 12 months of the study who were under the age of 40 (Pender 2010), leaving the experiences of older age groups and the changes during the honeymoon period unexplored.

Educational programmes and intervention studies in adult onset type 1 diabetes

In parallel with the systematic literature review of qualitative studies, the search was also amended to identify potential intervention studies and programmes aimed specifically at the adult onset type 1 diabetes population to explore what had already been developed for the adult onset population. The previous search for qualitative literature had identified MeSH, keywords and free text terminology in each database to detect studies on the population of adults with type 1 diabetes. These terms were combined with terms relating to intervention studies (e.g. intervention, programme, randomized controlled trial). Citations from meta-analyses and other key references were searched to extend study capture.

Title and abstracts were screened according to the following inclusion criteria:

- 1) Studies that described an intervention or programme specifically aimed at adults (>18 years old) who had been diagnosed with type 1 diabetes < 1 year before the start of the intervention

The electronic database search identified 1560 records, leaving 1464 records after removal of duplicates. Titles and abstracts of 1464 records were reviewed, and 1396 records were excluded as they did not meet the inclusion criteria. Full-texts of the remaining 68 records were obtained, and five studies were included in the review (see figure 4 on page 58).

Three of the five studies described educational programmes (Araszkiewicz et al. 2008, Berkeley et al. 2012, Shaban et al. 2013), one study detailed a psychological intervention (Spiess et al. 1995) and one study described an intervention carried out by a social worker (Gafvels et al. 2014). The methods and key components of these interventions are summarised in table 2 on page 59. All patients were diagnosed less than 1 year prior to participation in the intervention/educational programme which was available to all newly diagnosed adults at the providing clinics except for the study by Gafvels et al. which was aimed at patients with psycho-social problems.

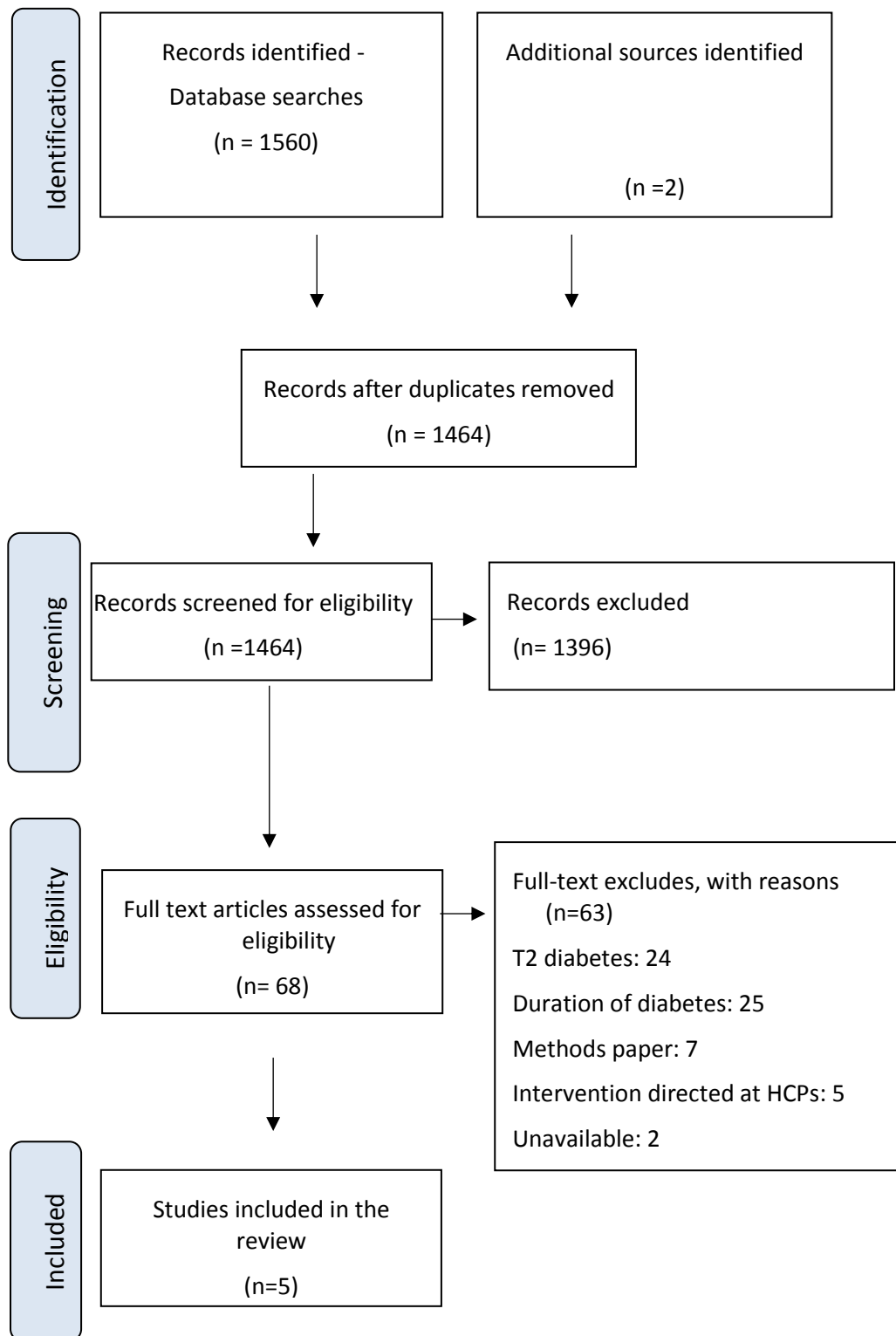


Figure 4 PRISMA flow diagram of database search for intervention studies

Table 2 Characteristic of intervention studies and educational programmes aimed at adults newly diagnosed with type 1 diabetes

Author, year, and country	Content of intervention/ programme	Evaluation	Study population	Outcome measures	Results
<p>Study 1</p> <p>Spiess K et al 1995, Austria</p>	<p>Intervention:</p> <p>25 sessions lasting 90 minutes addressing diabetes onset distress, delivered by a psychotherapist.</p> <p>Sessions focused on: expressing grief; dealing with future anxieties; and unconscious personality patterns</p>	<p>Randomised controlled trial with follow up after 9 and 15 months</p>	<p>Intervention</p> <p>N= 10; mean age 24.6 (5.29)</p> <p>Control</p> <p>N=13; mean age 24.5 (4.11)</p>	<p>HbA1c</p> <p>Questionnaires:</p> <p>Life events</p> <p>Depression</p> <p>Anxiety</p> <p>Coping</p>	<p>No difference in HbA1c at any time.</p> <p>At 9 months anxiety, depression and denial were reduced in the intervention group. At 15 months only denial was lower in the intervention group</p>

Author, year, and country	Content of intervention/ programme	Evaluation	Study population	Outcome measures	Results
Study 2 Araszkiewicz, A et al 2008, Poland	Five day structured group education programme focusing on principles on enhancing insulin use with a multiple-daily injection model.	Follow up after 7.1 (± 1.5) years evaluating association between baseline diabetes knowledge and micro-vascular complications	86 patients aged < 35 Mean age 23.4 (5.1), follow up after 7.1 (1.5) years	Baseline: HbA1c Questionnaire: Diabetes knowledge Follow up: Retinopathy Proteinuria	Low diabetes knowledge at baseline was associated with development of retinopathy (RR=3.71; 95%CI 1.15-12.01, $p= 0.02$) and microalbuminuria (RR=4.33; 95%CI 0.98-19.10, $p= 0.04$) at follow up
Study 3 Berkeley H et al. 2012, UK	Structured education programme delivered over 7-8 hours in groups aiming at increasing patients' self-efficacy in self-management. The programme focuses on bio-medical knowledge and technical skills	Pre-post-test comparing baseline to end of course	42 patients (characteristics not available)	Questionnaire: Confidence in self-management of diabetes	Increased confidence in self-managing various situations after participating in course

Author, year, and country	Content of intervention/ programme	Evaluation	Study population	Outcome measures	Results
Study 4 Shaban C et al 2013, UK	Structured group education programme with four modules spread over 1 year focusing on: managing blood glucose; psychological issues; long term health; carbohydrate counting	Pre-post-test with follow-up after one and three years, with a reference group from a historic cohort.	66 participants mean age 37.5 (14) These were compared to a historic cohort of 74 mean age 39.8 (15.4).	HbA1c Questionnaires: Diabetes distress Depression	No difference in HbA1c between historic cohort and participants in the new programme. No change was seen in diabetes distress or depression at follow up.
Study 5 Gafvels C et al 2014, Sweden	Psycho-social support, psychotherapeutic and crisis interventions carried out in one-to-one sessions lasting one hour by a social worker for a group of patients with identified psycho-social problems	Pre-post-test with follow-up after two years. Comparison with a group of patients without psycho-social problems	82 participants. 27 participants with psycho-social problems (14 with type 1 diabetes) mean age 40.6 years. 55 without psycho-social problems (23 with type 1 diabetes) mean age 42.6	HbA1c Questionnaires: Anxiety Depression Coping skills	Patients with psycho-social problems had higher levels of anxiety and depression, concerns over the future and lower SOC scores at baseline and follow up compared to those without psycho-social problems. HbA1c decreased in both group. Results were not specified according to diabetes type

The programmes and the interventions outlined above are limited studies in regard to description of the intervention, number of participants and evaluation of the intervention/programme. They focus on particular aspects during the first year following a diabetes diagnosis. While three of the examples included psycho-social aspects, these were not fully integrated with the physical aspects. Also, the programmes and interventions did not pay specific attention to the adaptive processes exceeding the first year following the diagnosis. Given the arguments presented in the meta-synthesis, more multimodal approaches might be better placed, drawing on the full bio-psycho-social adaptive model including all the aspects that adults diagnosed with type 1 diabetes encounter and also extending beyond the first year following the diagnosis. However, it is clear that an empirical study is needed to consider a better way of informing such interventions.

Chapter summary

This chapter has outlined the two theoretical concepts that underpin this study; adaptation and the bio-psycho-social model. The relevance of these concepts to the study was also explained. In addition, the chapter has described the current knowledge about adaptation in the adult onset type 1 diabetes population. Current educational programmes and interventions aiming at this population have been described briefly. Gaps in the current knowledge were identified to justify the need for an empirical study to further explore the bio-psycho-social phenomena of adaptation during the early years following a diabetes diagnosis. The following chapter will describe the study approach and the methods that were used in the empirical study.

Chapter 3 Methodology and methods

This chapter details the adopted research approach, design and methods for the study. The chapter outlines and discusses the rationale for the research approach in relation to the research question for the study. The chapter is organised into the following sections:

- Study aim and objectives
- Research approach
- Study design
- Ethical issues
- Data analysis
- Validity/trustworthiness

Study aim and objectives

The overall aim of the study was to explore the experiences of adaptation to life with diabetes from the perspectives of adults recently diagnosed with type 1 diabetes, to elicit the phenomena that inform the adaptive processes involved in this transition. A narrative, interpretive method was chosen for the study as this approach has the potential to capture personal experiences of change over time (Riessman 1993, Riessman 2008, Sandelowski 1991, Smith 2016). The narrative approach allowed the participants to elicit from their experiences the meaning they ascribed to this change in life and the phenomena influencing the process of adaptation involved in becoming a person with type 1 diabetes. Participants were recruited from settings in two different countries to enhance the possibility of exploring a wider range of experiences regarding the diabetes diagnosis and the adaptive process.

The study also had a longitudinal element as the review of current studies highlighted the need to consider a broader time frame when considering the period of transition following diagnosis. The study was designed to address the following research questions:

- What is the personal experience of adults of being diagnosed with type 1 diabetes?
- How is adaptation expressed in the experiences of adults following diagnosis considering the interplay between the biological, psychological and social phenomena within those experiences and their associated behavioural responses?
- What phenomena shape the adaptive process following diagnosis and how might these phenomena inform the development of more optimal strategies to support adults following their diagnosis?

The study objectives were:

- To explore the personal experiences and perspectives of adults with new onset type 1 diabetes in relation to adapting to a life with diabetes.
- To identify the underlying bio-psycho-social characteristics and phenomena that inform the adaptive process following a diagnosis with type 1 diabetes.
- To identify potential mechanisms that could be used to enhance the support provided and foster more positive adaptive strategies following a diagnosis of type 1 diabetes.

The following section will outline the study design and approach in more detail including the use of the MRC framework to guide the study.

Research approach

The intention of this study is to gain an in-depth understanding of the personal experiences and needs of adults who are newly diagnosed with type 1 diabetes. Such understanding is essential in optimising strategies for subsequent intervention. It is highly likely that any intervention targeting the transition into diabetes from diagnosis will have to be multimodal. As outlined in the previous chapter the process of adaptation into a life with diabetes is complex and will likely require a complex intervention with multiple time specific components, targeting bio-psycho-social and learning needs. Therefore, the approach for this study follows the MRC framework for

developing and evaluating complex interventions (MRC 2006). This framework has been widely adopted over recent years to inform complex intervention design. Complex interventions can be described as interventions containing several interacting components (MRC 2000, MRC 2006, Craig et al. 2008). The original framework introduced five sequential phases to provide a structure for the development and testing of complex interventions (MRC 2000). These phases were the preclinical or theoretical, the modelling, the exploratory trial, the definite randomised controlled trial and the long-term implementation, respectively. The MRC framework was revised in 2006 to be more flexible, it promoted a cyclical rather than linear approach (Craig et al. 2008, MRC 2006). The four key elements described in the revised framework are: development, feasibility and piloting, evaluation, and implementation. As outlined in the introduction this study is positioned in the development phase, where the initial focus is on assessing the evidence base (this was the focus of the literature review and meta-synthesis outlined in chapter 2) and existing theory in relation to the intervention (also outlined in chapter 2). It is also important in this phase to develop additional theoretical concepts that might elicit potential mechanisms for intervention. It is this latter part of the developmental phase that is considered in the methods presented in this chapter, although the approach and framing for the study is integral to the theoretical synthesis presented previously. Another key function of this part of the study is the direct involvement of people with diabetes and their experiences to contextualise the intervention with reference to their needs. Therefore, this study will provide a platform for the design (or co-design with patients) of the intervention for the next phases of the framework, which would be piloting and feasibility testing. Such an approach should enhance the utility, acceptability and hopefully the efficacy of the intervention as well as elaborating its theoretical context and mechanisms for action.

Given that the study questions aimed to explore the experiences and needs of the adult onset type 1 diabetes population from an individual perspective, it was recognised that the research approach required for the study needed to enable a deep understanding of the transition to a life with diabetes and the ensuing adaptive processes. The approach also needed to link with and build on the theoretical models developed from

the meta-synthesis and from existing theory describing the adaptive process in the transition to a life with diabetes (Whittemore and Roy 2002). The meta-synthesis described what is known about adaptation from previous research and identified gaps in the existing knowledge. These theories will be used to help interpret the experiences of adults following their diagnosis. However, in order to develop a clear theoretical platform for future intervention, it is important to develop new insights into the mechanisms of adaptation and the views of adults who have recently developed type 1 diabetes on what is important to them in adapting to a life with diabetes. Therefore, while the study approach needs to integrate the prior theoretical models and build on these models, it also allows for new insights to extend and challenge the models to create a new understanding of the adaptive process and the needs of adults transitioning into a life with diabetes. Given the focus both on the experience of the diagnosis and the phenomena and mechanisms underlying the ensuing process of adaptation to a life with diabetes, a longitudinal qualitative narrative approach for the study was adopted (Green and Thorogood 2014, Silverman 2010, Riessman 2008, Smith 2016).

Epistemological underpinning of the study

The qualitative approach is focused on people, the context they live in, the meanings they attach to their experiences of the world and how they make sense of their experiences (Creswell 2013). These experiences can be made available to the researcher through interviews, participant observation, video/audio or text analysis (Creswell 2013, Morse 2011, Riessman 2008). People's experiences of a specific phenomenon might vary and the underlying assumption in qualitative research is that multiple realities about the complexity of the phenomenon under study are available and acceptable (Creswell 2013, Green and Thorogood 2014, Morse 2011, Smith 2016). The knowledge that can be gained from exploring people's experiences is influenced by their thoughts, perceptions, and interpretations of the phenomenon, and is therefore a subjective account of the event (Riessman 1993, Riessman 2008, Sandelowski 1991, Smith 2016). The researcher then interprets people's perception of the phenomenon in order to provide a possible understanding of the meaning they

attribute to their experience of it (Riessman 1993, Riessman 2008, Smith 2016). Consequently, the knowledge that is gained is situational as it depends on the context, the participants and the researcher. It is partial as it is a reflection of multiple realities that potentially continue to change according to the interpretations of both the individuals and the researchers (Creswell 2013, Riessman 2008, Silverman 2010, Smith 2016).

The philosophical underpinning of this study is based in the interpretivist/hermeneutic tradition with the belief that phenomena can be observable but might be interpreted differently from one subject to the other (Riessman 2008, Smith 2016, Somers 1994). The interpretivist/hermeneutic stance was combined with a pragmatic approach utilising multiple data sources to capture the depth and breadth of adaptation to a life with diabetes (Patton 2002). In the context of this study measurable data such as HbA1c and duration of diabetes have also been included. These data sources are used to complement the qualitative data. The interviews explore people's understanding of their glucose levels, and their experience of living with diabetes over time, such as how they make use of and interpret the meaning of their blood glucose measurements. The data evolving from these multiple sources may help shed light on possible interactions between the bio-psycho-social dimensions influencing the experience of adapting to a life with type 1 diabetes (Bochner 2001).

Narrative inquiry

A narrative interpretative approach as described by Riessman (2008, 1993) was chosen as it affords the opportunity for the participants to represent their thoughts, feelings and events that they find significant in relation to their diagnosis and the process of adaptation over time when telling their story. Hence, the narrative approach is coherent with the longitudinal design of the study. The researcher is able to explore personal experiences of events situated in time and place and how these events are interpreted by the individual (Riessman 1993, Riessman 2008, Sandelowski 1991, Smith 2016). The personal narrative can unfold how people make sense of or find meaning in

what has happened to them and consequently the narrative contributes to making sense of behaviours and cognitions when people tell their stories about how they connect the multiple aspects of the diabetes diagnosis and interpret the impact diabetes has on their lives (Sandelowski 1991, Bamberg 2012, Bury 2001, Frank 2013). In addition, the narrative approach is well suited to explore transition and change over time by looking at what significant events during the process of change people choose to highlight in their stories (Riessman 1993, Riessman 2008, Smith 2016). Narratives have been defined in various ways and are often used synonymously with a story (Riessman 2008, Bamberg 2010). In some cases, narratives include objects other than spoken accounts, such as photographs, documents or medical records (Smith and Sparkes 2008, Davis 2008, Stuckey and Tisdell 2010). According to Miller (2000, p. 311), "Narratives are interpersonally constructed as people make sense of what is happening to them in relation to past events and future expectations and in relation to other actors." Narratives are therefore constructed in interaction with others and set in time and context by the narrator. As time and context change, the narrative might change accordingly (Riessman 1993, Smith 2016, Bruner 1991, Frank 2013). In the context of this study the sense-making of the diabetes diagnosis as experienced in the context of everyday life and the ensuing process of adaptation are explored. The underlying phenomena that drive this process are likely to unfold through the use of narrative as suggested by Polkinghorne: "We achieve our personal identities and self-concept through the use of the narrative configuration... we are constantly having to revise the plot as new events are added to our lives" (Bruner 1990).

There are various approaches to conducting narrative analysis drawing on different sources and traditions within qualitative research such as psychology (Bruner 1991, Smith 2016), sociology (Riessman 2008, Riessman 1990, Gubrium and Holstein 1998) and nursing (Sandelowski 1991, Holloway and Freshwater 2009). While some approaches focus on how the story is told – i.e. the structure of the narrative (Labov and Waletzky 1997) – others focus on what is told – i.e. the content and themes of the narrative (Williams 1984). Mishler (1995) and Riessman (2008) encourage researchers to combine the approaches if relevant for the research question. The appreciation of

time and the focus on how people order their experiences in temporal sequences is central to any type of narrative analysis (Bamberg 2012, Riessman 2008, Smith 2016, Gergen and Gergen 1988).

Riessman (1990; 1993; 2008) points out that the individual narrative is the focus of analysis exploring three essential elements; the text, the time and the meaning. The analysis of the text explores how the story is told, where the story is set, what characters are part of the story, what components of the story are highlighted and what parts are not included. Time is an important factor in the analysis in relation to looking at the consistency and change over time. Likewise, the temporal sequence in which the story is told is part of the analysis. Through analysis of the text and the temporal sequence of events the researcher interprets what meaning people attribute to their experience and what changes might have occurred, and also why the story was told in a certain way.

The analysis relating to the experience of diagnosis and the process of adaptation will focus on all three elements of the narrative. When exploring the experiences of diagnosis attention will be given to the structure of how people tell their stories (Riessman 2008) by looking at the temporal sequence of events they find important to talk about (Bamberg 2010, Riessman 2008, Smith 2016, Frank 2013) and also the setting and significant characters that play a role in the story (Miller 2000, Riessman 2008, Bamberg 2010). Furthermore, attention will be given to the impact on the experience and the events on participants' identity development and how they situate themselves in the story (Gergen and Gergen 1988).

Thematic narrative analysis assumes some kind of commonality across accounts from individuals who have experienced similar events (Riessman 2008) in order to develop meaningful themes that are applicable across the data set. Examples of ways thematic narrative analyses have been applied in other studies include Williams' study involving 30 people diagnosed with rheumatoid arthritis (Williams 1984). Williams explored people's perception of the genesis of their disease and paid specific attention to what

the participants told (the content) rather than the structure of the narratives (the how). Riessman utilised a combination of a thematic and a structural approach to the analysis when exploring experiences of divorce (Riessman 2008). According to Riessman (2008) the value of combining these two approaches to narrative analysis is to be able to capture commonalities (the themes) but also the distinction between the individuals and how the story is told. In her study on how members of AA (Alcoholics Anonymous) develop a way of telling their story, Cain (1991) also combined thematic analysis with a structural approach. Cain looked at the content of each person's story including similar themes that occurred. She also explored the way the story was told by identifying the sequence of essential events in the story, such as what life was like before joining AA, what happened after joining and what life is like now (Cain 1991). Yet another way of looking at how a narrative is structured is to identify the setting in which the narrative takes place and the influence the social setting has on how the narrative is shaped (Somers 1994, Gubrium and Holstein 1998). Somers (1994) spoke about this as different "dimensions of narrativity". These dimensions are: ontological or personal narratives, public narratives and meta-narratives. Ontological or personal narratives are devoted to subjective accounts of who we are and what we do to manage our life. Public narratives relate to the social context in which people live and are accounts defined by an entity that is larger than the single individual e.g. the immediate family (Somers 1994) or organisational structures such as health care professionals (Davis 2008, Miller 2000, Snow 2013). Meta-narratives can be both historical overarching stories at international level, such as capitalism vs communism, and stories about "culturally embedded expectations" of motherhood (Miller 2000) or management of chronic illness (Williams 1984). The meta-narratives might operate on a subconscious level but will nevertheless influence the stories we share (Somers 1994). In the analysis attention will be given to possible inconsistencies between these narratives and any effects they might have on how the participants tell their stories (Snow 2013).

In summary, narrative inquiry offers an opportunity to elicit accounts from the perspective of participants. These accounts enable an exploration of the personal

interpretation of the diagnosis and the underlying phenomena and mechanisms related to the process of adapting to a life with diabetes, by focusing on the content (thematic analysis) and the structure of the narrative including the plot, the characters and the meaning (structural analysis).

Study design

A narrative approach was deemed best suited to addressing the research questions and eliciting potential mechanisms for intervention. The way the study was designed and conducted will be explained in more detail in the following sections.

Given that one of the aims of the study was to study the process of adaptation, and time and change being central points in narrative methodology, a longitudinal design was adopted (Miller 2000, Riessman 2008, Snow 2013, Somers 1994, Murray et al. 2009). Longitudinal in-depth personal interviews were chosen to elicit narratives relating to the multifaceted process of adapting to a life with type 1 diabetes (Riessman 2008). Semi-structured interviews with open-ended questions were chosen as the data collection method to allow participants to share their stories focusing on issues they found important, as opposed to a structured interview with closed questions that would be more directive in relation to the data elicited (Kvale and Brinkmann 2009, Riessman 2008, Smith 2016). While the narrative longitudinal approach has been utilised to explore change in perception of diabetes over time in studies exploring treatment decision-making in young adults with type 1 diabetes (Pyatak et al. 2013), impact of patient education in adults with type 1 diabetes (Snow et al. 2013, Snow et al. 2014) and the meaning adults with longstanding type 1 diabetes ascribe to living with the illness (Stuckey and Tisdell 2010), it has not yet been used to explore the experiences of adults with new onset type 1 diabetes over time in a transnational sample. The longitudinal design afforded the opportunity to explore changes in experiences and perceptions and, importantly, give insight into the adaptive process over time.

Ethical issues

Before commencing with the study ethical approval was sought and granted from the appropriate regulatory authorities in the UK and Denmark (see appendix B). The procedures for obtaining ethical approval of qualitative research projects differ significantly between the two countries. However, the key ethical issues are the same and these will be outlined below.

In Denmark only research involving samples of human tissue requires ethical approval from the National Ethics Committee. However, approval to access sites is needed from the clinical leads at each site and permission to store sensitive personal information is needed from the Danish Data Protection agency. Information about the study including aims and objectives, inclusion and exclusion criteria for recruitment, and how data would be stored securely was given to the clinical leads from all sites in Denmark and all gave their consent to participate in the study. The Danish Data Protection Agency were given the same information and they approved the study in January 2015.

In England, the procedure of applying for ethical approval was followed as outlined in the Integrated Research Application System. Key ethical issues to consider when conducting the study were obtaining voluntary informed consent, conduct of the interviews including any potential harm to participants, and confidentiality of personal data. As I was not a resident in the UK at the time of applying for ethics approval, one of my supervisors, Dr David Hopkins was the Principal Investigator.

When inviting patients to participate in research projects it is important that they understand what the research is about and how participation might affect them. The application to the ethics committee detailed the purpose and the conduct of the study including what was expected of the participant in case they consented to participate. It was stressed that participation was voluntary and that it was possible to withdraw at any stage without any consequence for them. Participation in an interview might be a potential burden to participants as they are reflecting on experiences that might be distressing for them. Therefore, consideration was given to responding appropriately

to any concerns and a plan was in place prior to conducting the interviews (see appendix C).

Another issue pertained to confidentiality. Potential participants were informed that all data obtained from the interviews and the medical records would be treated as confidential and saved on a password protected computer. Actual names would be replaced with a pseudonym so that data could not be traced to specific persons. In future publications the pseudonyms will also be used. Measures were also taken to protect the anonymity of each participant by providing an age span rather than their actual age when presenting person specific quotes and data.

Patient and Public Involvement

Information about how patients and members of the public will be involved in the research is required when applying for ethical approval. Patient and public involvement (PPI) in research is defined as research being carried out with or by members of the public rather than on or to them and it is a way to make research more available to the public and for the researcher to gain a better understanding of the public's needs and how these might differ (Involve). PPI have become increasingly pertinent when developing and conducting research in the UK (Staley 2015, Domecq et al. 2014) PPI is essential when using the MRC framework to develop interventions (Craig et al. 2008, MRC 2006) and increasingly PPI is required when applying for certain types of funding. PPI has the potential to enhance participation as their influence on the study is likely to increase the subjective value for the participants (Domecq et al. 2014). Further, the value of PPI extends to influence the development of the most appropriate designs, methods of data collection, and potentially analysis and dissemination of findings (Domecq et al. 2014, Snow 2013).

In this study PPI groups have been involved both in Denmark and the UK. These groups acted as sounding boards for ideas, helped with development of patient information sheets, refined and piloted the interview guide and gave feedback on the preliminary analysis as described in more detail in the following section.

In the UK a Clinical Research Network-supported PPI group for people with diabetes in South London was already established and connected to one of the trusts in which the research was conducted. A diabetes specialist nurse, who is also a researcher, organised and led those meetings. Minutes from the meetings were distributed to all participants afterwards. The meetings lasted two hours during which four to five health professionals presented specific elements of their study that they would like the members' feedback on.

The members of this PPI group were a mixture in age, duration and type of diabetes, and most were over the age of 60 and had lived with diabetes for more than 20 years. This PPI group was consulted on two occasions. At an early stage of the PhD the study aim and objectives as well as the preliminary interview guide were presented to members of the PPI group. The members of the group were invited to comment on the relevance of the aim and objectives. While their own diagnosis had been made many years ago, they had vivid memories of that experience and found that the study was important with potential benefits to other patients. In addition, the members were asked to comment on the content of the interview guide and their view on the possible consequences of the interviews being conducted by me – a non-native English speaker. As a result of the feedback from the group, one of the questions in the interview guide was changed. The term acceptance was changed to 'coming to terms with' as the PPI group suggested that acceptance could be defined and understood in various ways. In regard to the potential language issues when conducting the interviews, the members of the PPI group did not anticipate any problems as long as I stressed that the participants could ask me if they did not understand me. According to their advice I emphasised to the English-speaking participants at the beginning of each interview that they were welcome to interrupt if they had trouble understanding me. Likewise, I asked them if it was okay with them to ask questions in case there were words or phrases I did not understand.

The PPI group was consulted later to discuss preliminary findings. The members of the group recognised their own adaptive process in the findings and they specifically highlighted that adaptation is a process that does not end even after more than 45 years with type 1 diabetes. While quite some time had passed since the members of

the PPI group were diagnosed, their extensive experience of living with diabetes and consequently the long-time perspectives they were able to provide added to the interpretation of the data and validation of the findings.

To provide additional perspectives, a patient advisory group was set up in Denmark, formed of nine adults who had been diagnosed with type 1 diabetes within the past seven years as they were more likely to remember details about their diagnosis and the early adaptive process. These adults were selected among participants who had participated in so-called Diabetes Dialogue meetings at a clinic in Denmark (Due-Christensen et al. 2016). The Danish patient advisory group was also consulted twice. To help me facilitate the meetings two researchers from the group I was connected to in Denmark were present. At the initial meeting the group was consulted in regard to the study aims and objectives. In accordance with the UK based group, this group found the study relevant and important. The members of the group were also involved in designing the patient information sheet and the invitation letter to ensure that information about the study was understandable for potential participants. After having presented preliminary drafts of the information sheet and the invitation letter to the whole group, the members were asked to discuss the content in groups of three and give feedback to the whole group. After some discussion the group agreed on final drafts which was then discussed with my Danish supervisor. A few minor changes were made to the wording (e.g. word tense) but the content remained as suggested by the PPI group. At the second meeting I presented preliminary findings to the group supported by quotes from the interviews. These were then discussed in groups of three before feeding back to the whole group. The members acted as sounding board for the trustworthiness of the findings. They gave constructive feedback and challenged some of the ideas which aided with the ongoing interpretation of the data.

In addition to the patient involvement in both countries, a professional advisory group was established from the start of the PhD study. The members of the professional advisory group were multi-disciplinary and included nurses with broad experience in qualitative research, medical doctors with extensive experience in research and

medical management of diabetes patients, and psychiatrists with vast experience in research and management of psychological aspects of care for patients with diabetes. The professional advisory group was convened on three occasions. Study aims and objectives and design were discussed at the first meeting. The members gave feedback and provided useful guidance for constructive modifications such as including participants with a diagnosis within the past three years as opposed to two years to explore more prolonged experiences of the adaptive process. Members of the group also suggested having the study adopted to the NIHR Clinical Research Network (CRN) portfolio and the address-2 database to extend the possibility of recruitment.

At the following meetings the progression of the study, the analytical approach and preliminary findings were discussed. Due to the time-consuming process of obtaining ethical approval the progression of the study was not as expected at the second meeting. In order to obtain the longitudinal data within the limited timeframe the advisory group suggested that the second interviews should be conducted over the phone. In addition to this helpful guidance, they also gave feedback on the analytical approach and the preliminary findings which helped with the ongoing interpretation of data. At the last meeting the advisory group reviewed and validated part of the findings as well as gave constructive suggestions on how to present the combined findings as the diabetes story.

Also, some members of the advisory group were approached individually for guidance on specific issues such as the literature review or theoretical perspectives to gain a better understanding of particular aspects of these issues.

Throughout the PhD I had regular meetings with my three supervisors. Most of these were individual meetings due to their affiliation with centres in different countries. However, in addition to the advisory group meetings we had at least one annual joint face to face meeting and a number of skype meetings to discuss particular aspects of the study. The feedback from the supervisors were extremely valuable throughout the study process and their thought-provoking questions and guidance enhanced the credibility of the findings.

Setting

As mentioned in a previous section, the data were collected in two countries in order to widen the perspective in relation to exploring the experiences of a diabetes diagnosis in adulthood and the adaptive process following the diagnosis.

Within qualitative approaches, emphasis is put on the context in which the data were collected as the knowledge that is produced is context-dependent (Green and Thorogood 2014, Patton 2002, Silverman 2010). The contexts in which the participants are diagnosed and live their lives influence how they experience the diagnosis and the way they adapt to diabetes, and therefore there might be considerable variations in their experiences. In the following section the care pathway for adults newly diagnosed with type 1 diabetes is outlined along with contextual information about Denmark and England.

People's experience of diagnosis might influence how they contextualise diabetes. The acuteness of symptoms prior to diagnosis determines whether or not they are diagnosed at their GP or in hospital (i.e. if they are brought to A&E with DKA). It might also be influenced by whether or not they have had experience with type 1 diabetes beforehand, their exposure to diabetes education and clinical follow up after the diagnosis, and whether or not they are in a relationship, have children or are working.

Most often an initial diagnosis of diabetes is made by the GP in primary care who will respond in accordance with the symptoms people are presenting with. Depending on the severity of symptoms, the person will be admitted to the hospital or referred to a specialist clinic that can initiate insulin treatment. In line with the national guidelines (NICE 2015, Danish Endocrine Society 2016) a multiple daily injection basal-bolus insulin regimen is initiated from the onset of diabetes. An individual plan for their care is developed and includes frequent clinical follow up consultations initially and structured education that will enable self-management of diabetes. People with type 1 diabetes are seen in specialised clinics in tertiary care in both countries. These clinics usually provide a multidisciplinary service to people living with type 1 diabetes with access to consultations with dietitians, nurses and doctors. The way that people engage

with the services and their perceptions of the care they receive is likely to influence their experience of living with diabetes and impact their adaptive process.

As outlined in the introduction the study was conducted in urban settings in Denmark and England. Both countries are affluent societies. Access to welfare and standard of living are comparable between the two countries. The education systems are comparable in primary and secondary schools but differ in higher education in terms of access, as higher education is free in Denmark and educational aid from public funds is available, whereas tuition has to be paid in England. In both countries access to health care for all citizens is based on need rather than ability to pay. The health care system is financed through income taxes. Training of health care professionals is comparable in content and length. The 2014 WHO ranking of health systems places the UK at number 18 and Denmark at number 34 (Tandon et al. 2014). Medication for treatment of chronic conditions is free of charge in England (NHS) whereas people who live in Denmark have to pay for their medication up to a certain amount (approx. £350 per year).

Sampling strategy

Within the narrative approach there are not specific guidelines in relation to sample size or strategy (Smith 2016, Riessman 2008). Each individual narrative is considered valuable in its own right, as it provides contextual knowledge about how a person experiences and makes sense of an event. As outlined previously, there might be variations and commonalities in both the experience of the diagnosis and adaptation to life with diabetes according to age at diagnosis and time lived with diabetes and therefore a larger and diverse sample was required to capture these potential differences.

Qualitative researchers recommend sampling the amount of data that will enable an in-depth exploration of people's experience that provides a new insight and understanding of that experience across a range of people (Sandelowski 1995, Coyne

1997, Malterud et al. 2016). The systematic review demonstrated that previous research into the experience of diagnosis and adaptation to diabetes have involved small samples representing the target population. Therefore, to gain knowledge about various experiences of the diagnosis and reach a deeper understanding of adaptation to type 1 diabetes, this study aimed to involve a larger, more diverse group of adults recently diagnosed with type 1 diabetes to elicit detailed accounts of their experience across the adult age span and across the first three years of living with type 1 diabetes with roughly equal numbers of women and men from each country. A heterogeneous sample would enable an exploration of a diversity of experiences and perceptions (Green and Thorogood 2014, Riessman 2008, Smith 2016). While the restriction of a duration of three years enabled participants to talk about their experience of diagnosis within a limited time frame; it also ensured that participants had recent experiences of adapting to diabetes. The variation in age at diagnosis could potentially provide rich information on similarities and differences in the experience of the impact of diagnosis across the adult age span. The range in duration of diabetes might offer different perspectives on the process of adaptation and reveal potential significant periods or moments. In order to elicit a diversity of narratives reflecting the above-mentioned criteria the aim was to recruit fifteen adults from each country, amounting to 30 participants in total. This number of participants was similar to other studies exploring experiences of chronic illness (Williams 1984) and exploring perceptions in different nationalities (Green et al. 2005). Sampling strategies vary between study designs (Patton 2002, Crabtree and Miller 1999). In this study a purposeful sampling strategy with maximum variation of the sample was chosen. Purposeful sampling aims to select participants that are most likely to provide rich information about the experience. The variety of participants is likely to yield a diversity of experiences and perspectives across the participants and in addition information on patterns that are common across the sample (Patton 2002, Crabtree and Miller 1999).

Inclusion and exclusion criteria

The following inclusion and exclusion criteria for recruitment to the study were set up to enable data collection in a sample of adults with new onset type 1 diabetes who

would have sufficient experience of living with diabetes to provide the in-depth understanding needed to answer the study questions. Inclusion and exclusion criteria will be listed in the following section and then further explained.

To be included in the study participants had to:

- Be diagnosed with type 1 diabetes at age 18 or older;
- Have been diagnosed within the past three years; and
- Speak Danish or English.

Participants would be excluded from the study if they

- Had severe mental illness; or
- Were pregnant.

As mentioned in the introduction, the experience of diagnosis is well researched in children and adolescents and likewise the transition from adolescent to adult care has been explored in detail (Rasmussen et al. 2011), but knowledge is lacking regarding the experience of being diagnosed in adulthood. The age at which adulthood begins can be contested, and various descriptions regarding adulthood have been applied to different age groups. While emerging adulthood has been described as the period between 18 and 30 years by some (Luyckx et al. 2010), others mention this period as ranging from 14 to 25 years (Oris et al. 2016). In the context of this study adulthood is seen as the period starting at 18 when a person becomes of age and is legally independent. It is, however, acknowledged that huge variations in experience are likely to be present within and across the wide range of ages recruited for the study. In relation to other studies on diabetes there is not always a clear division between adolescence and adulthood. However, people who are diagnosed at age 18 or older will be referred directly to an adult clinic at all the participating sites.

Defining 'newly diagnosed' as 'having diabetes for three years or less' was chosen to explore the process of adaptation during a longer period of time, allowing the narratives to describe various experiences and adaptive processes that might take

place during this time frame. While it is well established that physiological changes take place during this initial period of life with diabetes, such as the differences in insulin requirements during the honeymoon period (Davis et al. 2015), little is known about how these physical changes affect the adaptive process. Knowledge about the psycho-social adaptive process during this time is also scarce.

The longitudinal design afforded the opportunity to explore the adaptive process over time. While the time frame for the PhD introduced some limitation to the interval between the interviews, six months was deemed an appropriate period. It allowed the participants to go through some of the physical and psycho-social changes which provided a platform for understanding more about their process of adaptation (Calman et al. 2013).

The study participants were included from two different countries and in order to enable a clear understanding of their experiences during the interviews, they had to be English or Danish speaking.

Participants were not eligible if they had a severe mental illness or if they were pregnant as the experiences relating to such conditions in conjunction with being diagnosed with type 1 diabetes are distinct and only applicable to a small sample of the study population.

Recruitment

Before including a clinic as a recruitment site, consideration was given in regard to appropriateness for selecting participants for the study who were able to elicit in-depth accounts of their experience of adapting to life with type 1 diabetes (Crabtree and Miller 1999, Silverman 2010).

While the population of adults with new onset type 1 diabetes is relatively small; specialised diabetes clinics with sizeable numbers of patients were deemed suitable for recruiting a diverse group of participants with experiences of the diabetes diagnosis across a three-year period. The choice of settings was somewhat pragmatic in regard to historical connections to either my supervisors or me in relation to previous or

present work commitments or research collaborations. From a pragmatic point of view these connections also made access and permission to recruit participants (Creswell 2013) manageable within the timeframe of the study. Because the study focuses on people's experiences of adapting to a life with diabetes rather than comparing and contrasting experiences from one clinic to another, centres with a comparable approach to care for adults with type 1 diabetes were selected. All recruitment sites are situated within the capital area of each country, they serve a socio-economically diverse population and have extensive experience with caring for adults with type 1 diabetes from the time of diagnosis and onwards in the trajectory of life with diabetes. Three clinics in Denmark were involved in the study (study sites A, B, and C) and two clinics in England (study sites D and E).

In the UK, the study was adopted by the NIHR Clinical Research Network (CRN) portfolio and the address-2 database. The CRN provides a database of clinical research studies taking place in the NHS and offers help in recruiting patients. The address-2 is an online platform sponsored by Imperial College London and funded by the Juvenile Diabetes Research Foundation and Diabetes UK to make people with type 1 diabetes aware of research opportunities and connect potential participants with researchers. Information about the study was made publicly accessible through their websites and it was therefore possible for potential participants and health care professionals to find the study. Members of the CRN team aided in the recruitment process by approaching potential candidates at the sites in London.

The multidisciplinary teams at all study sites were informed about inclusion and exclusion criteria prior to initiating recruitment to the study so that they would be aware of potential eligible participants in their clinical encounters. Members of the clinical staff at the recruitment sites provided lists of potential eligible patients with type 1 diabetes diagnosed within the past three years. Information about their next clinical appointment was also available. Potential participants with a clinical appointment within the next two months were screened for eligibility according to inclusion and exclusion criteria. Inviting participants with clinical appointments within

the following two months provided an opportunity to approach them at the clinic if they did not reply to the letter of invitation. In addition, if they agreed to participate, the interview could take place when they attended their appointment if they preferred this and hence they would not have to spend additional time travelling. When reviewing potential candidates, their age, duration of diabetes and gender was taken into consideration when possible before sending a letter of invitation to balance the sample according to these criteria.

As it was impossible to know how many eligible participants would consent to take part in the study, a larger number of invitations than required for the study were sent to eligible participants. Twenty eligible patients at study site A, all eligible patients at study site D (n=12), and 20 eligible patients from study site E were invited to participate in the study.

The letter of invitation contained information about the study and information on how to get involved in the study (see appendix D). Participants who were interested in learning more about the study were asked to return a reply slip in a stamped addressed envelope or to contact me by email or phone. Subsequently, any who responded received written information about the study (see appendix C) and I contacted them to discuss participation and answer potential questions.

If the potential participant in England had not replied to the invitation prior to their clinical appointment they were approached in the waiting area by a member of the clinical team, a member of the CRN team or myself to inquire whether they were interested in discussing participation in the study.

In Denmark, potential participants received a phone call if they had not replied to the letter, to ask if they were interested in learning more about the study before deciding whether or not to participate. The Research Ethics Committee in England did not approve the use of reminder phone calls. The concerns of the panel are likely related

to ensuring that participation in the research was voluntary and not forced. Due to these restrictions potential participants in England were not approached by phone.

Study sites B and C were approached late in the recruitment period in order to involve adults from more than one centre in Denmark in the study. These sites were not able to provide specific lists with information regarding the inclusion and exclusion criteria. In consultation with the clinical team at site B one potential participant was identified and invited to participate in the study. At study site C a diabetes specialist nurse made direct contact with eligible patients at their clinical appointments and invited them to participate in the study. The differences in recruitment approach may have excluded eligible participants from participating in the study. However, due to time constraints and practicalities around conducting the interviews this alternative approach was deemed appropriate to recruit a small number of patients.

When it was time to invite participants to take part in the second interview they were contacted by email.

Data collection

Data were collected through longitudinal semi-structured interviews to elicit rich details about their experiences and to allow the possibility of exploring potential change not only in the participants' perceptions but also in their description of these experiences over time (Calman et al. 2013, Riessman 2008). The first round of interviews was conducted in participants' home, work place, a room in the clinic or an office at the university. The second round of interviews were conducted over the phone (see chapter 4 for more details).

Riessman argues that the multiple realities available are constructed and constantly revised in interaction between the individual and their social context (Riessman 2008). The data are co-constructed between the interviewer and the interviewee as the response to the story, any probing questions and the interactions between the two will influence the way the story is told and how the data are constructed. The context in

which the data are collected and the interaction between the participant and the researcher influence the co-creation of data as the participants' view of the researcher and their interpretation of the study's objectives may shape their responses (Green et al. 2005, Patton 2002, Smith 2016).

The longitudinal design afforded the opportunity to develop a trusting relationship with the participants. I sought to do that by establishing rapport with them during the initial interview in that the first few minutes were spent talking about mundane issues such as how they got to the place of the interview or, when conducting interviews at their home, asking questions about the area they were living in. At the second interview I was able to follow up on personal information they had shared such as how their wedding went, to show them that what they had shared was important. In addition, referring to experiences they had previously shared and asking further questions regarding these signalled that their narratives had been listened to and were valuable.

A semi-structured interview guide (see appendix E) and two dialogue tools that encouraged participants to reflect on how diabetes had impacted their lives were used for the interviews. The development of the interview guide and the use of the two dialogue tools will be described in the following section.

The two tools were: The Pictorial Representation of Illness and Self-Measurement - Revised (PRISM-R) (Klis et al. 2008) (see appendix F) and "Room for diabetes in your life" (see appendix F), a dialogue tool developed as part of a Guided Self-Determination intervention (Zoffmann 2004). These tools were introduced to the participants at the end of the interviews to give them an opportunity to use illustrations rather than words to describe the impact diabetes had on their lives.

The interview guide questions were developed and inspired by the theoretical framework and findings from the meta-synthesis in collaboration with the PPI groups

in Denmark and the UK. The questions were open-ended and afforded the participants a possibility to extend the narratives they wanted to share (Kvale and Brinkmann 2009, Riessman 2008) as opposed to closed questions that would be directive of what participants were able to share.

As suggested by Kvale and Brinkmann (2009) the interview guide and the use of the dialogue tools were piloted before commencing with the study. Three people from the Danish patient advisory group (two Danish speaking and one English speaking) were interviewed. The interviews provided a platform for me to practice my interview skills and try out conducting the interview in English. Following each interview, the interview technique, the dialogue tools and the questions were discussed with the interviewee. The pilot interviews provided information about the understanding, the relevance and meaningfulness of the questions and the dialogue tools. The pilot interviewees deemed the dialogue tools relevant and appropriate to use for the interviews. The questions in the interview guide were revised according to feedback from the pilot interviews so they were more open rather than pointing in a specific direction. I.e. the opening question was originally posed as "Please tell me what happened in your life around the time you found out something was not well with your health" but was changed to: "Tell me what happened when you were diagnosed with type 1 diabetes." This way of framing the question was more in accord with principles of narrative interviewing in the fact that it is not directed at certain events but allows the participant to decide what events they regard as important when describing their experience of the diagnosis of diabetes (Riessman 2008).

The interview guide was also discussed with the PPI group in England and further revisions were made according to their feedback (see page 76).

The pilot interviews were recorded but not transcribed. The recordings afforded me the opportunity to listen to the way I asked the questions and how I engaged with the person during the interview. When listening to the recordings I became aware of my tendency to sometimes ask two-in-one questions and likewise there were some instances of interrupting the person while he or she was speaking. This made me more cognisant of how important it is to be as clear as possible and ask one question at a

time, as well as giving the person time to finish their sentences without interrupting them in order not to control the direction of the interview.

Conducting the interviews

Before commencing with the first interview the aims and objectives of the study were reiterated to the participants. Participants were asked for permission to record the interviews and they were made aware that the recordings would be transcribed for the purpose of analysing the content of the narrative. Confidentiality and anonymity were also discussed with participants. They were informed about the way the interview would be conducted such as the recording, my use of the interview guide and the dialogue tools and the expected time frame. It was emphasised that they had the opportunity to decline to answer any question they might find upsetting or inappropriate and that engaging with the dialogue tools was optional. While I explained to all participants that clarifying questions might be posed to explore my understanding of the content of their narrative, I additionally asked the English-speaking participants for permission to ask questions regarding words or phrases that I was not familiar with. All participants were told they could terminate the interview at any point if they wished to do so. I explained briefly my background as a diabetes nurse but that in this context my role was that of a researcher. Lastly, I gave the participants the opportunity to ask me any questions they might have. Written informed consent was then obtained from all participants before commencing with the interview (see appendix G).

The revised interview questions were used to guide the interview (see appendix E). The sequence of the questions varied from one interview to the next and was guided by the participants' narratives and their accounts of their experiences. Probing questions such as "and then what happened?" allowing pauses and mirroring questions using their own words to encourage further reflection, were used when appropriate to elicit additional information (Kvale and Brinkmann 2009).

When the interview ended I spoke to the participants about the possibility of them feeling upset following from the reflections on their experiences and asked them if they were okay with having participated in the interview. I explained that I was available for a phone call or email if they felt a need to follow up on the interview. In addition, the Danish participants were made aware that they could contact the clinical team if they needed additional support and the English participants were provided with a telephone number to the Patient Advice and Liaison Service at their hospital.

Apart from information about my background all the above information was repeated for the second interview.

The interview guide was revised for the second interview to focus more on what the participants thought was the most significant thing that had happened since the last conversation in relation to their diabetes (appendix E) and any changes in their perception of living with diabetes that might have occurred. The transcription of the first interview was read through before conducting the second interview to familiarise myself with each person's narrative. Probing, pauses, and mirroring questions were used and, when appropriate, points discussed in the first interview were referred to in the second interview.

After each interview I wrote field notes detailing the context of the interview and any additional comments the person might have made after the recording was terminated. In addition, I made a note of my own reflections on the conduct of the interview and potential areas to be mindful of in the following interviews (for an example of field notes see appendix H).

Transcription and translation of interviews

All the interviews were transcribed verbatim in the original language by different transcribers. The transcribers were given instructions to transcribe verbatim including

pauses and utterances such as audible sighs and crying. This was done to keep the text as close to the interview as possible and to make the co-construction of the narrative visible (Riessman 2008, Smith 2016, Holloway and Freshwater 2009). Pauses shorter than 2 seconds were illustrated by three dots (...) whereas pauses of up to 5 seconds were illustrated with (p) and pauses of longer duration were illustrated as (P). If the transcribers did not understand or were not able to hear a word or a phrase they noted the time on the recording in brackets i.e. [6:32]. All participants were given pseudonyms in order to ensure anonymity. Also, in case their title or place of work would compromise their identity, these would be changed or omitted from the interview (Malterud 2001, Kvale and Brinkmann 2009, Silverman 2010).

The interviews that were conducted in Denmark were translated by a Danish professional but not certified translator. The UK based interviews were not translated to Danish as the DK based supervisor is fluent in English.

The purpose of the translation was to provide the UK based supervisors an opportunity to read thorough whole transcripts from both countries. This allowed them to get a sense of what was going on in the narratives thereby providing insight and an overview of the data that enabled them to challenge my interpretation and add to the rigour of the analytic process.

Data analysis

A narrative approach to analysis offers a palette of possibilities for analysing the data rather than a fixed process to follow. For this study the process described by Riessman (2008) outlined earlier in this chapter has been used as a guidance to the analysis. The focus of analysis in this study was the participants' narratives about their experiences of being diagnosed with type 1 diabetes in adulthood and their transition into a life with diabetes. The first series of interviews was analysed before commencing with the second round of interviews. The analysis focused on similarities and differences among and between the narratives in relation to the content (the themes) and the structure (the setting, the timeline and the characters). The diabetes stories as portrayed by the participants were then described, followed by theoretical models for potential

intervention in relation to enhancing support for adults diagnosed with type 1 diabetes during the first three years of their life with diabetes. In the following, the steps taken to analyse the interviews will be outlined.

The first step of the analysis was to ensure the accuracy of the transcriptions by comparing all transcripts to the recordings to check for words that were not understood, as well as misinterpretations of words and phrases. The original transcriptions and the corrected versions were kept for documentation. The interviews were then imported to a qualitative data analysis software programme (NVivo for Windows 2012), to assist with the organisation and coding of the data. This and the following steps were repeated for the second round of interviews.

This first reading of the interviews gave an initial sense of what was going on in each participant's story. As suggested by several narrative researchers (Gergen and Gergen 1988, Smith 2016) a short summary of the content of each narrative, describing the immediate sense of their experience of being diagnosed with type 1 diabetes and the process of adaptation, was made after I had read their story (for examples, see appendix I). The summaries contained information about the temporal line of participants' narratives including how they began their story and any expectations they might have for their future process of adaptation. The summary also described what I interpreted as the main issues they raised during the interview. These summaries were created as memos in NVIVO and linked to each participant. Also, the field notes were added and linked to the relevant participant in NVIVO.

Following from that, the interview transcripts were read through several times to gain further familiarisation with each person's story and get a sense of what was going on throughout the narratives. After this, each narrative was coded in NVIVO. The data were coded in larger chunks rather than word by word or line by line in order to keep the narratives intact.

In the following section the analytical process will be explained in further detail.

Structural analysis

The structure of the narratives was identified by focusing on the main characters and the settings in which their stories were played out. In addition, attention was given to the temporal sequence of their stories and which topics were privileged or silenced, to identify what participants found important and what areas they spoke about briefly or not at all. This approach was in line with previous studies exploring narratives of cancer patients (Davis 2008) and expert diabetes patients (Snow 2013). In the following section the structural analysis is described in more detail.

Characters and settings

When applying a narrative approach to analysis it is suggested that researchers identify the characters and settings described in participants' narratives that may have importance when interpreting how participants make sense of what has happened to them (Riessman 2008). Codes were developed in NVIVO identifying the characters and settings that might influence the participants' experiences of diabetes. An example of codes relating to specific human characters were 'partner's reactions' and 'diabetes' impact on friendship'. In addition to the human characters, diabetes was also identified as a main character in its own right throughout the participants' narratives. Codes were developed to label how participants described the impact diabetes had on their lives and how they viewed diabetes. These codes were developed as a mixture of *in vivo* codes, derived directly from the participants' own words, for example 'the shitness of having diabetes' and 'diabetes is relentless' or as an interpretation of their narratives, such as 'multiple faces of diabetes'. The full coding tree for diabetes can be found in appendix J. Settings in which the narratives were played out were also coded, an example being 'work'. Interactions were explored to get a sense of what was going on, where it was going on and who was playing a part in their story. A document detailing the various characters and settings along with their specific relationship to the participants was created in MS Word after finishing the coding procedure. This was done to get an overall sense of who was playing a part and where, as a preparation to writing up the findings.

Temporal sequence and privileged and silenced stories

The temporal sequence of participants' stories indicated what events they found were important to relay when speaking about their experiences of living with diabetes. To explore the sequence of the events participants spoke about, a separate document was created in MS Excel detailing the order in which participants spoke about certain events. It was also noted if the interview changed direction due to participants mentioning new events, or to questions from me. The sequences of events in relation to their process of adaptation were compared across the participants and also indicated what events and stories were spoken about spontaneously across the narratives and what events were less common to speak about.

Thematic analysis

The interviews were also coded according to the themes that emerged from the narratives. The initial coding was inspired by the bio-psycho-social framework, the 'adapting to diabetes mellitus' theory and the findings from the meta-synthesis. Attention was given to bio-psycho-social phenomena that participants described in their narratives as influencing their experience of the diagnosis and the adaptive process. Within each phenomenon several child nodes that reflected various aspects of the phenomenon were developed from the narratives and then aggregated into parent nodes. This process is detailed in the following section.

Examples of codes in relation to the bio-psycho-social aspects were: 'handling high blood glucose' and 'hypoglycaemia' (biological/stabilisation); 'coming to terms and acceptance' and 'feeling sad' (psychological/integration and self-identity); and 'communicating diabetes' and 'peer support' (social/integration and relationships) (see appendix J). In addition, the themes that had emerged in the meta-synthesis were taken into account when coding the narratives. Examples of themes identified in the meta-synthesis were: 'learning to live with diabetes' and 'diabetes' impact on life context'. Again, these themes were expanded inductively to include several child nodes that detailed various aspects of these themes in further detail, to allow for

development of new knowledge about the participants' experiences and perceptions. Each person's narrative was coded using words or sentences that reflected a main point of their narrative. In some cases, chunks of the narrative were coded several times to allow for alternative interpretations of the content (see appendix J for an example). The child nodes were then aggregated into coherent themes that reflected the initial framework but also the new themes that had emerged from the participants' specific stories (see appendix J).

In addition, metaphors were explored and coded both in a separate node and in relation to how participants used the metaphor to describe the characters in the story, their approach to life with diabetes, or their process of adaptation.

The next step after coding the narratives was to look for similarities and differences between the themes expressed in the narratives. The quotes pertaining to each node were transferred to a MS word document to explore similarities and differences across the participants' narratives. These quotes were organised according to which country the participants originated from to get a sense of similarities and differences between the countries. The analysis also focused on parallel and opposing stories both within the individual narratives from each country and across the participants' narratives to explore different perspectives of life with diabetes.

Participant quotes were then used to discuss preliminary themes that emerged from the data with supervisors, members of the PPI groups (see page Z) and other colleagues to enhance the credibility of the findings.

In summary, the steps described above were taken to interpret the narratives and generate a deeper understanding of the experience of being diagnosed with type 1 diabetes in adulthood, and to explore the underlying phenomena involved in the process of adapting to a life with type 1 diabetes.

Reflexivity

When doing qualitative research, it is important to have an awareness of and acknowledge how and in what way the researcher might impact the research (Morse 2011, Riessman 2008, Silverman 2010). This influence needs to be transparent, and reflections on how the research has been influenced should be reported (Green and Thorogood 2014, Riessman 2008). The narrative approach acknowledges that data from narrative interviews are co-constructed between the interviewer and the interviewee (Gubrium and Holstein 1998, Riessman 2008, Smith 2016). The participants in this study were told that I am a nurse by background and that could potentially influence their expectations of what would be asked about during the interview. They might have certain conceptions about what a nurse may expect regarding their answers and topics they wanted to talk about and these conceptions might influence what they wanted to share in relation to their experiences, especially as some interviews were conducted in the clinical setting after their clinical appointments. In addition, some were recruited by the clinical staff, which could be an implication of the interview focusing on the clinical outcomes that they would usually speak with the health care professionals about. This was to some degree evident in the fact that the majority of participants answered the first question by telling their medical story around the diagnosis. This may suggest that they might have perceived the context of the interview as resembling a clinical appointment, which might have stopped them from sharing any difficulties up front. However, their awareness of my extensive experience as a diabetes specialist nurse might also have facilitated a trusting atmosphere as participants revealed details about their challenges at a later time during the interviews. It is likely that some of these challenges became apparent to them while they tried to make sense of their experiences in response to the interview questions illustrating the co-creation of the narrative.

It was a challenge for me to take on the role of a researcher who was not involved in caring for and supporting the participants in managing their diabetes. This challenge became evident during one of the pilot interviews in which I gave suggestions to a problem the interviewee brought up. This incident emphasised the need to be very

attentive in relation to not engaging in trying to offer specific support when participants shared information about their challenges during the interviews. It was particularly difficult to refrain from offering support when participants lacked knowledge or seemed to have misunderstood information that they had been given. In such cases, when the interview had come to an end I suggested that the participant made an appointment with their diabetes team to discuss any questions about their treatment. Largely I was able to remain in the role as the researcher but when listening through the recordings and reading the transcripts I identified a few incidences and described them in the field notes taken following the interviews.

The idea to conduct the study originated while I was practising as a diabetes specialist nurse and had consultations with many adults from diverse backgrounds living with diabetes for shorter or longer periods of time. While I have encountered many adults who have struggled with managing their diabetes, there have also been some who seemed to negotiate the demands of diabetes with less effort. It was evident from my clinical experience that there were various ways of approaching a life with diabetes which may have an impact on how people manage their diabetes long term.

My interpretation of their stories as they were conveyed to me during clinical appointments or previous research projects I have been involved in played a part in choosing the research question and designing the study. In order to be aware of my own perceptions about the experience of being diagnosed with type 1 diabetes and the process of adaptation I articulated my own thoughts about this on paper before beginning the research. For example, a perception was that being diagnosed with type 1 diabetes in adulthood is always perceived as a negative experience. This insight helped me to guard against asking leading questions during the interviews.

In addition, throughout the research process I made notes of my thoughts and also made these available to be challenged by the advisory groups as well as other researchers and specifically my supervisors so that I would not be limited in my

interpretation of the interviews by looking for specific answers to my research questions.

Validity

Within the narrative approach it is recognised that the data that are collected for analysis are co-constructed between the participant and the researcher. It is also acknowledged that the narratives participants share is their subjective interpretation of the events they are speaking about rather than an objective account of what happened (Riessman 2008). Therefore, the question of validity within narrative inquiry involves different criteria than those pertaining to quantitative research where reliability, objectivity, and internal and external validity are used to judge the research (Green and Thorogood 2014). Likewise, the analytic process is influenced by the perceptions and beliefs of the researcher, demanding transparency and reflexivity throughout the research process.

When assessing the quality of qualitative research, criteria such as trustworthiness, reflexivity, transferability and relevance are used (Green and Thorogood 2014, Malterud 2001, Silverman 2010). According to Riessman trustworthiness in narrative inquiry refers firstly to the credibility of the data that is collected (the participant's story) and secondly to the interpretation presented in the analysis (the researcher's story) (Riessman 2008). To enhance the trustworthiness of the data, measures were taken to recruit participants with appropriate experience of a diagnosis and transition into a life with type 1 diabetes so that they were able to share their perceptions and experiences in relation to this. Patient and professional advisory groups were involved in various parts of the research process to enhance the interpretive and theoretical validity of the study.

In addition, to enhance the trustworthiness of the interpretation of the interviews, a rigorous and transparent process was followed throughout the analysis process. This process was described in detail earlier in this chapter and the underpinning theoretical

framework was outlined in chapter 2. Direct quotations from participants will be used to support the interpretations and will be presented with the findings in the following chapters. As suggested elsewhere (Tong et al. 2012, Riessman 2008, Smith 2016) reflections on how I as a researcher may have impacted the collection and interpretation of the data have been detailed previously in this chapter.

Another way of addressing validity or trustworthiness in qualitative research is the transferability of the findings. As opposed to quantitative research where transferability is termed generalisability and refers to the possibility of generalising findings in relation to a specific occurrence to a larger population (Britten 2011), transferability in qualitative research refers to the possibility of transferring findings from one situation to another (Green and Thorogood 2014, Malterud 2001). Findings in a qualitative study are context specific, and the context in which they were collected must therefore be taken into account when assessing the transferability to other settings. However, the theoretical knowledge that is produced as an interpretation of the study findings in relation to the study question might be transferable to other people in similar situations or settings (Green and Thorogood 2014, Smith 2016, Riessman 1993, Riessman 2008). The validity of the study is given further consideration in the discussion of the study findings presented in Chapter 7.

Chapter summary

This chapter has outlined the study aims and objectives and the rationale for the design of the study including why the narrative approach was chosen. Information on the settings, the sampling strategy and how the data were collected have also been presented in the chapter. The analytical process has been outlined in detail including reflections on the validity of the research and ethical issues in relation to the conduct of the study.

The following chapters will detail the findings from the analysis of the interviews. Chapter 4 gives details of the recruitment process and describes the sample in greater depth. It also considers the context of the findings in relation to the transnational

sample. Chapter 5 is the main findings chapter detailing the findings in relation to the process of adaptation to a life with diabetes and identifies the phenomena and mechanisms that shape and influence this process. Chapter 6 suggests a series of theoretical models expressing these phenomena and mechanisms to inform a framework for the development of enhanced interventions for adults with newly diagnosed type 1 diabetes.

Chapter 4 Study participants

This chapter provides an overview of the study participants and gives details of the recruitment process, as a prelude to the main findings chapters. Consideration is also given to the context of the study addressing the recruitment process in the UK and Denmark.

Recruitment

As outlined in the previous chapter, the study aimed to recruit a diverse sample of participants in relation to age at diagnosis and duration of diabetes with equal representation of men and women. This section details the process and outcome of recruitment individually for the two countries.

Recruitment in Denmark

Of the twenty people who were invited from study site A, five replied via email stating their interest in the study. The remaining fifteen participants were approached in one of two ways. Five potential participants were approached personally by me at the diabetes clinic when they attended their clinical appointment. Those who did not have an immediate appointment ($n=10$) were approached with a telephone call. Potential participants were given the opportunity to ask any questions they may have about the study. Three of the people who were approached personally, either face-to-face or by phone declined to participate, two due to time constraints and one did not give a reason. Three did not respond to the invitation and could not be reached by phone; and two others could not commit the time for a face-to-face interview within a reasonable timeframe due to personal circumstances. Therefore, a total of 12 people was recruited from study site A. Two additional patients were recruited, one who was identified by the clinical staff in study site B; and another from study site C, who was approached by the diabetes nurse, agreed to participate in the study after having received a letter of invitation. Hence, an overall total of 14 adults with type 1 diabetes from Denmark participated in the study.

Recruitment in the UK

Of the 12 eligible participants from study site D, three returned the reply slip, one replied by email and after getting more information about the study they consented to participate. All four were interviewed. At study site E, 20 letters of invitation were sent out and ten participants returned the reply slip or emailed to agree to participate. However, it was not possible to make an appointment for the interview for two of those within a reasonable timeframe; one due to unforeseen workload and the other due to travelling abroad.

As mentioned in chapter 3 (see page 84), the clinical staff at each site had been informed about the inclusion and exclusion criteria for participating in the study. Two participants who had not received the initial invitation letter were referred to the study by members of the multidisciplinary team. One participant made contact by email after having seen the study on the Address2 website. Another participant identified their interest to participate after having heard about the study from a friend who had already agreed to participate in the study. These four participants agreed to participate after having received more information about the study. Therefore, 16 adults with new onset type 1 diabetes living in the UK participated in the study.

Conduct of the interviews

The first round of Danish interviews was conducted between April and June 2015 and the interviews in the UK between July and November 2015. The first interview with each person was conducted in a place of their choice that was convenient for them. Face to face interviews were held in: their home (n=6); their workplace (n=2); a clinic room (n=15); or in a private room at the university (King's College London) (n=7). The interviews lasted between 00:45 and 01:33 hours (median 01:08 hrs). The second round of interviews took place approximately six months later, and were conducted as telephone interviews. Twenty-eight of the 30 participants took part in the second wave of interviews which lasted approximately 25 minutes (the exact duration is not stated as there were several occasions where the connection caused problems).

Participant characteristics

The thirty adults who participated in the study were aged from 20 to 67 years (median 29 years). Sixteen of the participants were male, and the duration of their diabetes ranged from three to 46 months (median 23.5 months). Among the UK participants there was an equal split between men and women, whereas more men than women were interviewed in Denmark. The majority of participants were of White ethnicity, were in a relationship and were working full-time. HbA1c values at diagnosis were available for 25 participants and, as would be expected, this value was higher than the value at the first and second interviews when they had commenced with insulin therapy.

The two tables below detail the participant characteristics, Table 3 outlines the combined demographic details of the group and Table 4 describes individual details using the pseudonym allocated to each participant. Characteristics include the age span at diagnosis (median 27.5 years, IQR 22.8-45.3 years), at and the first interview (median 29 years, IQR 26-47.3 years) and diabetes duration at the first interview (median 23.5 months, IQR 9.8-32 months). Information is also provided regarding the participants' HbA1c at diagnosis (median 111 mmol/mol, IQR 85-130), at the time of the first interview (median 48 mmol/mol, IQR 42-64), and the second interview (median 52 mmol/mol, IQR 43-70) where data were available.

Table 3 Demographic breakdown of sample

Country of residence		
	UK	16 participants
	Denmark	14 participants
Gender		
	Male	16 participants
	Female	14 participants
Ethnicity		
	White	28 participants
	Other	2 participants
Latest educational qualification		
	GSCE/O level	2 participants
	A level	6 participants
	Degree	6 participants
	University degree	16 participants

Employment status		
	Student	2 participants
	Full time	23 participants
	Part time	4 participants
	Unemployed	1 participant
Civil status		
	Single	12 participants
	Married or living with partner	12 participants
	In a relationship (not cohabiting)	6 participants
Age at diagnosis		
	18-20	4 participants
	21-30	15 participants
	31-40	2 participants
	41-50	3 participants
	51-60	3 participants
	61-70	3 participants
Age at interview		
	20-30	15 participants
	31-40	6 participants
	41-50	3 participants
	51-60	2 participants
	61-70	4 participants
HbA1c at diagnosis mmol/mol (%)		
	Up to 69 (8.5)	2 participants
	70-86 (8.6-10.0)	4 participants
	87-108 (10.1-12.0)	5 participants
	109-130 (12.1-14)	8 participants
	131 – 171 (14.1-17.9)	6 participants
	Information NA	5 participants
HbA1c 1st interview mmol/mol (%)		
	37-42 (5.5-6.0)	7 participants
	43-48 (6.1-6.5)	9 participants
	49-59 (6.6-7.5)	4 participants
	60-69 (7.6-8.5)	5 participants
	70-80 (8.6-9.5)	2 participants
	81-91 (9.6-10.5)	2 participants
	92-138 (10.6-14.8)	1 participant
HbA1c 2nd interview mmol/mol (%)		
	37-42 (5.5-6.0)	5 participants
	43-48 (6.1-6.5)	6 participants
	49-59 (6.6-7.5)	4 participants
	60-69 (7.6-8.5)	5 participants
	70-80 (8.6-9.5)	3 participants
	81-91 (9.6-10.5)	2 participants
	92-138 (10.6-14.8)	0 participants
	Information NA	5 participants

Table 4 Individual characteristics of the sample listed according to order of the first interview.

NA indicates that information was not available

Name (pseudonym)	Country	Age band at diagnosis	Diabetes duration at 1st interview	HbA1c at diagnosis (mmol/mol)	HbA1c 1st interview (mmol/ mol)	HbA1c 2nd interview (mmol/ mol)
Kurt	DK	41-50	38 months	NA	59	61
Alice	DK	61-70	33 months	NA	41	40
Lene	DK	61-70	34 months	151	55	63
Dan	DK	18-20	31 months	113	40	44
Kaj	DK	51-60	23 months	112	41	40
Mie	DK	18-20	19 months	93	47	63
Tom	DK	21-30	32 months	105	64	72
Emil	DK	21-30	3 months	111	48	51
Mark	DK	21-30	28 months	87	48	51
Hans	DK	41-50	28 months	162	76	80
Jonas	DK	18-20	24 months	123	57	71
Pia	DK	41-50	9 months	77	44	48
Inge	DK	51-60	16 months	171	138	83
Stina	DK	21-30	16 months	66	70	85
Jane	UK	21-30	5 months	133	38	37
Jack	UK	31-40	4 months	126	84	84
Sue	UK	21-30	4 months	77	48	48
Bill	UK	21-30	46 months	NA	61	NA
Kath	UK	31-40	24 months	137	43	53
Lisa	UK	21-30	35 months	119	48	60
Ruth	UK	61-70	27 months	111	40	44
Nick	UK	21-30	17 months	NA	53	NA
Adam	UK	21-30	19 months	79	44	43
John	UK	21-30	31 months	60	60	43
Judy	UK	51-60	5 months	134	67	68
Helen	UK	18-20	32 months	83	48	53
Bob	UK	21-30	13 months	91	37	42
Amy	UK	21-30	38 months	115	81	NA
Andy	UK	21-30	15 months	91	41	40
Tony	UK	21-30	5 months	NA	64	NA

Transnational aspect of the study

From the outset of the study it was the intention to analyse the interviews to identify country level similarities and differences within the narratives. A somewhat surprising finding was that the experiences participants expressed throughout their narratives across the two countries were remarkably similar. While some variations in the care pathways were detected between the two countries, the experiences of the diagnosis and the following process of adaptation seemed to have much convergence across the two countries. One example of variations in the care pathways was how insulin treatment was initiated. In Denmark patients were given rapid acting insulin according to their blood glucose every two to four hours for three full days after their diagnosis before they were put on a basal/bolus regimen. In the UK, however, patients were immediately put on such a regimen. However, this difference during the first few days did not seem to influence the participants' experiences. The similarities were apparent both in their descriptions of their experiences and even in how they expressed these, as the words and phrases they used were very similar. As the similarities between the narratives from the two countries became evident it was decided to analyse the interviews as a whole data set rather than two separate data sets. Chapter 5 will describe the participants' experiences in more detail, however, a few examples of similar words or expressions of experiences are outlined below to underline the commonalities contained within the narratives between the countries.

When describing how diabetes is something they constantly have to either think about or directly manage, two young women used the same expression to illustrate their feelings about diabetes:

Sometimes it just feels really tedious. You know when you're just, like, tired and you just want to have to not think about something, and you just still have to think about it? (Helen, UK)

You know it's really tedious. Measuring blood sugar and taking insulin four times every day. (Mie, DK)

For people who were single, the experience of dating had changed after they were diagnosed with type 1 diabetes. Two participants reflected on what kind of emphasis

they put on having diabetes when they were out on a date. Nick, who is from the UK, said:

I've been on a few dates since, and I must admit, I've never brought it up on a first date. (P) It...I just – I do feel there is still quite a stigma around – I'm just going to say diabetes, just for the moment, without bringing anything else into context about it, because of just actual sort of general awareness of what the illness is and what it does, and I think when you sort of initially try and explain that to someone, all they see is 'chronic illness', and that's what you have, and that you're going to just die.

And Stina from Denmark also described how she approached the subject on a first date:

Well, I probably wrap it in cotton wool, you know, avoid talking about the chronicity and all the things that might happen when you get older and all of the things one is more exposed to. I avoid talking about it because it's not something that adds value or something that adds value to me [chuckles]. So yes, it gets... I water it down and say, 'Oh it's just insulin and that's just how it is, and then you live healthy', and talk about the positive stuff instead of pointing out the negative stuff, yeah...

Another reflection that was common across the two countries was the difficulty of relating to the seriousness of having diabetes. Emil from Denmark was confronted with the seriousness of diabetes after having experienced a severe hypoglycaemia:

And then I realised how serious it was, sort of. I had to face the fact that you can actually die from it.

While Kath from the UK expressed how she tries to avoid thinking about the seriousness of diabetes:

I never thought about how serious it actually was and I still don't, you still sort of hide from that, how serious it is, you just get on with it because if you sit and think how bad it is, you know, that you could die from it, you know, that's like really bad, and I don't think you do.

Where heterogeneity in participant experiences was identified, it was not related to country but mainly to personal perceptions and the amount of life lived before the

diagnosis. Those who were diagnosed when they were younger (in their late teens and their twenties) seemed to respond differently to adapting to life with diabetes than those who were older. The younger participants were in a process of developing their identity and making adaptations to form their lives and their careers and seemed largely to be able to make something positive out of their diagnosis. A common statement was that they now appreciated life more and had become more aware of their health and their values. On the contrary, the older participants had already formed their identity and settled with ways of conducting their lives that gave them a sense of meaning. The diabetes diagnosis challenged their sense of identity and direction, causing them to uproot their set ways and make adaptations that they felt negatively affected their quality of life. The differences between the age groups and the various perceptions of the diagnosis and the process of adaptation will be further explored in chapter 5.

Chapter summary

This chapter has described how participants in both countries were recruited to the study. Characteristics of the participants who were interviewed were presented both on a group and an individual level. Reflections on the transnational aspect of conducting the study were then outlined and justification for analysing all data as one data set was given. The following chapter presents the main findings that emerged from the participants' narratives in relation to their experience of being diagnosed with type 1 diabetes and the adaptive processes that follow the diagnosis.

Chapter 5 Findings

This chapter presents the narratives that emerged from the interviews with 30 adults recently diagnosed with type 1 diabetes. These narratives form the 'diabetes story' as described through the participants' collective experiences of the diagnosis. The story also relays the process of adaptation to a life with diabetes and identifies the phenomena and mechanisms that shape and influence this process. As outlined in chapter 3 the narrative approach involves both a structural and thematic approach. The chapter is organised into two sections detailing:

- The structure of the narratives in regard to the settings, the main characters and the plot lines that emerged from the individual narratives.
- The main body of the narratives reflecting the collective diabetes stories and the themes expressed within those narratives.

Section 1: The narrative structure

This section will describe the settings, the main characters, and the plotlines within the narratives. Describing the various settings in which their stories unfold is essential to contextualising the participants' narratives. The characters are important as they relay the significant relationships the participants identify within their experiences in adapting to a life with diabetes. These characters can either be actual persons or metaphorical constructions. In addition, attention is given to the plotline including privileged and silenced stories within the narratives. The privileged stories are those that are explicitly articulated by the participants or by others whereas the silenced stories are those that provide insight into the adaptive process but are spoken about only briefly or are dismissed. These findings will later be considered in relation to the temporal sequence of the narratives and the themes that were developed through the analysis.

The scenes

Within participants' narratives the lived experience of being diagnosed with diabetes and adapting to life with the condition was played out across a series of scenes. Each

scene provided the context for both common and unique experiences of the participants and how these informed their perception of diabetes. These scenes were: their life prior to the diagnosis; their new interactions with the health care system; and their everyday life following the diagnosis, such as in their home, their work, and the wider society. The scenes are described below according to the participants' experiences of adapting to diabetes.

Scene 1. Life before their diagnosis

While the participants' stories generally started with their experiences around the diagnosis, accounts of their past lives were a common reference for how they relayed their experiences. A core feature of this scene was that it was a more spontaneous life with the ability to move easily from one activity to another without giving it too much thought.

Participants also referred to their views and behaviours related to their health prior to their diagnosis. While participants may have tried to live a healthy life-style in general, more specific thoughts or concerns about their personal health did not feature prominently in this scene. They also related previous experiences of ill health which were largely transient episodes, these were contrasted with the experience of diabetes as a disease without end. Health concerns became more prominent in this scene when the early symptoms of diabetes began to emerge prior to their diagnosis. The participants' references to their prior life were used to contrast their experiences at and following the diagnosis. The contrasting experiences informed their perception of the diabetes diagnosis and affected their adaptation to life with diabetes. Their views about health prior to the diagnosis largely determined how they reacted to the initial symptoms of diabetes. The nature of these symptoms in terms of their acuteness and severity influenced their initial approach and experience with the health care system in their quest to find out why they were unwell.

Scene 2. Interactions with the health care system

Once the participants experienced symptoms of diabetes they entered a new scene as they sought help from health care professionals within the health care system. For many this scene was in the context of their general health reference point: their GP practice. However, for some participants with more severe symptoms their initial experiences were in more acute care settings such as accident and emergency (A&E) departments. In all cases the participants were subsequently referred to specialist hospital diabetes teams where treatment with insulin was initiated. Hence, for many, this meant that they suddenly found themselves in a new life context in unfamiliar surroundings. This scene introduced new characters to the participants' stories. They encountered multiple health care professionals who provided information about diabetes and technical support to initiate their adaptation to life with diabetes. This new context then became a more routine aspect of the scene as regular contact with the health care system was required for their continuing support. In addition to the clinical environment in the hospital with its waiting and consulting rooms, they also experienced other health care contexts such as the ophthalmic screening and foot assessment departments. Another feature of this scene was that they needed to familiarise themselves with the world of chronic disease and make connections with other services; they needed to resource their diabetes care, such as organising appointments and collecting prescriptions. Collectively such interactions created time and organisational pressures in their lives.

Scene 3. Everyday life with diabetes

This scene expresses the transformation that takes place in the day-to-day lives of people following their diagnosis. This is a dynamic scene, with constant change and adjustment as the person tries to adapt their diabetes in their daily habitus. The scene is played out in multiple contexts including their home, their work, and in wider society. These contexts can often be quite divergent, with different forms of adaptation being played out in each. In some cases, participants introduce strong barriers between these contexts, with the participants playing different roles in each.

The home

The diabetes diagnosis demanded significant changes to the environment and routines that defined the participants' everyday home life. In terms of physical changes, participants had to find space in their home for insulin, needles, blood glucose meters and lancets. Such equipment needs to be available for them when they wake-up, before having meals, when they go to bed and during the night. Overall, these items become the manifest artefacts of diabetes in their physical space as well as a visible sign to those around them that they are a person with diabetes. The diabetes also introduced new routines into their home lives. The simple task of buying groceries now demanded extra attention. Apart from remembering to buy milk for their tea, they had to make sure that a supply of fast-acting carbohydrates was available in their home in case of hypoglycaemia. Other activities such as doing laundry, cleaning the house or doing gardening likewise affected their self-management as these activities could potentially lower their blood glucose, whereas sedentary activities such as watching a movie could increase their blood glucose. Hence, their home space was disrupted by their diabetes: what had previously been a place of rest, was now disrupted by the constant demands of their diabetes.

The work place/study

All but one of the participants were either studying or employed, and as with their home lives diabetes changed their work/study environment. There were variations between participants in how this scene was organised. In part this was related to the nature of their work/study environment, how much control they had over that environment and how understanding their employer was. While for most participants, the diagnosis did not affect their work and they could carry out the same type of work as they did prior to the diagnosis, it did have an impact on their work environment, routines and patterns in the work-place. Again they needed access to supportive equipment and had to adjust their work to accommodate breaks for injecting insulin, testing blood glucose or managing hypoglycaemia. While most workplaces encouraged the participants to be open about diabetes and sought to give them space to manage diabetes, for some conducting self-management activities were difficult. In their

perception, their employer or manager did not sufficiently understand or sanction their need for self-management. Another feature of this scene was an underlying insecurity about their abilities to perform their work roles as well as uncertainty about their future career options and choices.

The wider social context

A challenging scene for participants was their experiences in wider social settings, such as going for a meal or a drink with friends and/or family, going to the gym or travelling. When engaging in these activities the participants now had to take diabetes into account. This scene could be quite complex for some participants. In the ideal scene they would be open about their diabetes and have the self-management resources they needed at their disposal in each situation. However, it could also be quite a dark scene where participants felt awkward about their diabetes and tried to conceal its presence.

In summary, across the narratives diabetes was played out in the context of their everyday lives such as their home, their study or work and in wider society. This new addition to their life context led to several adjustments and adaptations in relation to the way they conducted their daily lives as illustrated by Kath (thirties, T1D 24 months):

It's the first thing you think of when you wake up; 'Am I alright?' You have to check, either I am or I'm not, but you've got to go and have an injection straightaway anyway even if that's not for food, that's your basal to cover you for the day. And then, 'Right I need to eat', so you've got to think about what you're going to have. It consumes you. It is consuming. If you're eating carbohydrate and it's new to you, it is all consuming. 'Right, I'm going to walk to work but before I leave I must check what I am.' But you sort of go into... it's not like if you tell somebody who's not diabetic that it would be like 'oh my God', but you sort of you get on with it, that is how it is. So then you get to work, 'Oh I best check what I am because people are going to come in, I don't want to be about to hypo,' because that's obviously the most scariest thing especially in

front of other people, so you check again, and then just all day really you're thinking, if your eyes go fuzzy you think 'Oh am I too low or am I too high? Either way I need to sort it out so I best check what I am. 'So you check again. And it's like that all day! [Laughs] And if you're at home, if you're in a relaxed environment, it's not so bad, you do relax a little bit but it still is in most of your thoughts, but obviously if you're at work and I don't do an active job but I still was very much... like if they said to me 'Oh can you go and do a viewing', which I didn't always do, I'd be like 'Oh yeah, sure', just check what I am and then 'Oh I need to have a sweet, God I've got to go and talk to somebody on a viewing, I'm going to eat a sweet to make sure I'm high enough, perhaps too high, to make sure I don't hypo', and then you come back, sit down, it's like 'Right am I too high, should I correct, am I...?' you know, it's just basically 'Am I OK?' all the time.

The characters

Within the narratives and the experiences expressed by the participants there were significant characters that informed how the participants described their transition into a life with diabetes. These characters were both physical and metaphorical. The characters also changed across the scenes of the narratives. The main physical characters were themselves, their friends and family, health care professionals and peripheral acquaintances. The key metaphorical character in the narratives was diabetes itself, as a new entity that was now cohabiting in their lives. These characters are described below as reflected in the narratives expressing the roles they enacted and the common and divergent features of each character group in the narratives of the participants.

The person with diabetes

The protagonists in the narratives were the adults newly diagnosed with type 1 diabetes. The most significant feature of the character of the person with diabetes was that it was a character in transition and it was often an uncertain character. The

transition element of the character relates to both the identification of diabetes in their life contexts and the resolution with their past life. Their uncertainty was also multifaceted, reflecting both their immediate life change and their questions about the future. The transition and the uncertainty features were integral to the character and played both with and against each other, as illustrated by Adam (twenties, T1D 19 months):

Adam: Erm, the only thing that ever crops up occasionally is the occasional when you've got too much time on your hands and start thinking about what are the potential consequences of some of the side effects. Erm, I don't know, not the nicest thoughts in the world...

Interviewer: What do you do if they crop up?

Adam: Well, I ... think about coming back to the fact that I will try to manage it the best I can and I'm doing the best I can to ensure that they don't happen, but it doesn't mean that they don't crop up every now and again.

Family and friends

Family and friends are significant characters throughout the participants' stories, as the diabetes diagnosis also affects significant others and the relationship the person with diabetes has with them. These characters are expressed in terms of the type and quality of the relationship between them and the person with diabetes (bearing in mind that this characterisation is emergent from the narrative of the person with diabetes). Hence, the character can be very variable and plays according to the patterns of interaction that occur (or are perceived to occur) in that relationship. A driving feature of these interactions in the diabetes context can be how the significant other expresses their concern for the person with diabetes, this can range from disinterest to excessive interference with the daily diabetes experience. One end of the continuum is illustrated in this quote from Judy (fifties, T1D 5 months):

My eldest son, who has the children, he's super, super healthy. He's awful. And he just went, 'Oh, thanks, Mum. That means I'm going to get [diabetes]'.

Another aspect of the significant other character is their role as watcher. This role can be related to giving the person some feedback on their behaviour, perhaps when their glucose is too low, or in a more judgemental sense watching how well they observe their diabetes self-management practices. Lisa expresses how she feels about interference in this extract:

I went on holiday with my Mum for a week and there's always been like contentious issues of her saying all the time 'What are your levels?' and 'Have you tested recently' and stuff and so on holiday I was like 'There's only one way that I'm going to do a test' and she was like 'What?' and I'm like 'If you say "Testicles I'm dead"' [laughter]. It was like 'Oh God and I won't do it'. And so now she says 'testicles' instead of test and it just makes like more light of the situation and also she's aware of when she's saying test and how that level of, not like embarrassment and shame that she has in saying testicles is almost the same level that I feel of kind of going 'Oh, I've got to test' in a way 'Oh, I've got to say the word'. (Lisa, twenties, T1D 35 months)

Health care professionals

Health care professionals played multiple roles, reflecting the different types of professionals the participants were exposed to. Some characters, like their GP, were already in their lives; others, such as the diabetes specialists, were new. However, following their diagnosis the roles of all these characters changed. Now they were health care professionals relating to someone with a chronic disease. The professional characters also varied in their level of understanding and experience of diabetes and their approach to diabetes. In terms of understanding, this reflected their level of training and expertise which differed between the GP, junior doctors, consultants, nurses, and dietitians, all of whom may or may not be specialised in diabetes. In relation to the approach of the professional, this could be in terms of the style of communication and what they thought the person with diabetes needed to do or know. Hence, these characters could be perceived as being either facilitators or directors, with the former working with them to help them understand while the latter tells them what to do. These character dimensions are not necessarily viewed as good

or bad by the person as it can be that a more directive approach is found to be helpful on some occasions. Another feature of these characters is the language they speak, with the participants having to learn the diabetes language including such terms as: hypoglycaemia; HbA1c; 'injection site rotation'; and your 'insulin carb ratio'. The professional character can also be viewed as the judge and as a controller, deciding what they should do and whether they are being successful as a person with diabetes, as illustrated by Mie (twenties, T1D 19 months):

The health care professionals do their best and want the best for you, but it's still kind of weird that others are in control of your life. You have your weight measured and have a blood glucose test done and [they are] looking at your blood glucose levels. Even though all of it is for my sake it's weird that others are kind of in control of you.

While overall the amount of time spent with health care professionals is limited, the role these characters play is significant in influencing the adaptive trajectory of the participants.

Peripheral acquaintances and the general public

Peripheral acquaintances such as the larger body of co-workers, students or friends were other characters in the participants' stories. Their role was mainly relayed as the onlookers to participants' self-management of diabetes which could change depending on how much the participants chose to reveal about their diabetes in different contexts. Although their direct involvement in diabetes may be limited and their understanding of diabetes superficial; they occasionally took on the role of assessor to pass comments and judgement on the participants' behaviours, such as questioning their food or drink choices. The extent to which acquaintances featured in the story was filtered by the participants. Sometimes they may be open about their diabetes. Other times, if they were concerned that revealing their diabetes could trigger prejudice against them, they would be closed. The general public also played a part in their stories. Participants were aware that when they experience hypoglycaemia in public the people around them may potentially observe them, make a judgement

about them and have to assist them in managing the hypoglycaemia. In the latter context the member of the public would become a rescuer. Reflecting on his various interactions with people, Nick (twenties, T1D 17 months) said:

Because I've got this stuff on me, it's quite noticeable, and it's that whole thing about prejudice, again, and how I feel like I'm being perceived in a way. It's also been hard having hypo in public, when you just feel like a drunk idiot and you're trying to get yourself just back into normality again and this has happened a few times (...) There's been one occasion in the middle of doing my job where I've been feeling it and I know we're in the middle of something and I just do not want to bring this up, and it just got to that stage where it took over me and... and it did the worst thing it could have done and it sort of brought everyone's attention on me, they stopped doing what they were doing and, yeah, that was just... it was just that embarrassment of that. But it was also a bit of a wake-up call as well, 'cause I didn't let the others know that I had diabetes so no-one knew what was going on and sort of went on from that experience to... making sure that people knew I guess.

Diabetes

Diabetes was the most prominent metaphorical entity in the narratives. Diabetes was depicted as having independent agency and intentionality in the participants' stories. Participants used a multitude of metaphors to describe their perception of various features of diabetes and ways that it had affected their lives. Sometimes the metaphor portrayed diabetes as a person, other times as an object. One participant compared having diabetes to being in a relationship, however, a relationship that she did not choose voluntarily and now feels trapped in:

Unfortunately, it's become a follower I have to live with for the rest of my life (...) Like my husband, I also have to have him in tow (laughs). (Inge, fifties, T1D 16 months)

Their perception of diabetes as a relentless component of their lives was often expressed in metaphors detailing their thoughts and feelings about diabetes and their

self-management responsibilities. One participant described the tenacity of diabetes by comparing it to the dependency of a baby:

You can resent it a little bit and it's exhausting because it's like carrying a baby around with you the whole time, you always have to take care of it, you can't leave it in the room and walk out, you can't take your eyes off it and in the same way as sometimes some parents want to leave the baby with the grandparents for the weekend and just go and relax, sometimes I would like to be in a different body for the weekend, one that isn't diabetic. (Andy, twenties, T1D 15 months)

These metaphors expressed their frustrations and anxieties about a life with diabetes, defining its challenging, unpredictable, constantly changing and demanding nature which could almost be compared to having a teenager around:

It's always changing. Because it doesn't seem to behave the same day in, day out. (Adam, twenties, T1D 19 months)

Besides making reference to family members, some participants applied metaphors of a competition or a battleground when they described their view of diabetes. For example, one participant portrayed diabetes as a challenger that he was forced to contest and confront:

I chose that on day one of being diagnosed, I said 'I've got this and I'm going to absolutely smash it', like I do, I'm going to be 100% on this, because I don't have a choice. (Bob, twenties, T1D 13 months)

Participants also identified the potential harm diabetes might do to them if they were not successful in controlling it, which they perceived as a constant underlying threat. In this way diabetes was seen as a persecutory entity, as expressed by Jane (twenties, T1D 5 months):

So...keeping my sugars steady so that I can feel confident that it's not going to come back and bite me and I'm not going to get complications.

Echoing this more maleficent view of diabetes, another participant with multi-morbidity compared having diabetes to being at the mercy of a lethal enemy:

But diabetes, no, it's been a killer from day one, it's been a pain in the arse from day one, and it's not something that's easy to accept. (Jack, thirties, T1D 4 months)

This anxiety about complications was a core part of their identification of the meaning of a life with diabetes.

Participants described other features of diabetes through metaphors relating to various objects or characteristics. A common view among the participants was that they experienced limitations and restrictions in their day-to-day life. They felt constrained in their ability to be spontaneous because they were constantly cognisant of the presence of diabetes in their lives and they perceived it as relentless and interfering with their activities demanding constant attention. For example, one participant said:

I think that's the thing... that you can't switch it off. That, like... yeah. I don't know. Always having to just think a little bit more than everyone else about what you're doing and, like, what you're eating, and you need to inject yourself...that kind of thing. (Helen, twenties, T1D 32 months)

Another aspect participants referred to was the metaphorical weight of diabetes. They compared it to always having to carry a heavy backpack. However, there were also physical and visual signs of the diabetes character as participants had to carry their actual devices with them. The baggage metaphor as a sign of diabetes was common among participants, as expressed by Nick (twenties, T1D 17 months):

I don't like always having to have my stuff on me. I think that's always been an issue. I've always been quite light when I go out. I have my phone, my keys, my wallet and that's the way I do my life... and I never have a bag. Never had a bag. So now that I have to take those extra things with me, I've started wearing, like, a little man-bag, on occasions, when I'm going out, which I got quite used to. But it's just that sort of added baggage, both literally and metaphorically, that I guess has had quite an impact on me. And it's quite a visual cue, as well, in a way. I sort of see it and I think, 'Oh, God, this is what I've now got to carry around

with me.’ Gosh, I didn’t mean this to turn into a metaphor, ’cause it wasn’t meant that way, but that’s... yeah, that’s been quite hard.

In line with the view of diabetes being demanding and taxing, a number of participants collectively described diabetes as a ‘shitty disease’ (Mark, Pia, Jonas and Andy). Some participants felt that the role diabetes played in their lives was all negative, while for others its role developed over time. For some participants it took on a positive role, being described as a motivator or a coach facilitating positive changes in their lives, as illustrated by Bill (twenties, T1D 46 months):

It’s made me very strong, it’s made me consider my health, it’s made me have better relationships with people... it’s made me find my passion in nutrition, it’s made me find my passion in helping people, it’s made me actually have a better relationship with my father, it’s made me have a better relationship with my Mum... I now appreciate things so much more because, in a way, when I was so ill... I was never really ill beforehand. I hated getting a cold. And when I was really ill, I kind of was like... it was almost a big... I don’t want to be cliché about it, but it was almost a wakeup call coming. OK, life is precious, as it were, but... it made me kind of go, ‘OK, I’ve got to start looking after myself and I’ve got to change because I have to. I’ve got a responsibility’. I want to make... I don’t want to worry Mum, as I said before, or my parents. I don’t want to feel awful. So... and in line with that, it’s made me much more confident and happy. So even though diabetes is a condition or a disease or whatever words you put on it, it’s really helped me develop myself.

Diabetes is a main character in the collective narratives. Participants use metaphors to portray characteristics of diabetes that illustrate their perception of the impact it has on their lives and as such it plays a significant role in the plotlines of their narratives and the themes relating to the adaptive processes following their diagnosis.

Narrative plot

Once the scenes and the characters from the narratives had been outlined, consideration was given to the plot lines underpinning the participants' stories. Within the narrative approach, it is important to identify the overall structure of the participants' narratives. What events do participants speak about? How are these events constructed into episodes that reveal how people make sense of the events and their temporal sequence? On the whole participants attempted to make meaningful connections across their past, present and anticipated future when sharing their stories about living with diabetes. There was a common structure in the events participants spoke about in reply to the open-ended question: *'Please tell me what happened when you were diagnosed with type 1 diabetes'*. Participants' stories began with accounts of their experiences related to the physical symptoms around the diagnosis and the disruption it brought about in their lives both physically, emotionally and socially. Participants then spoke about their need to learn about what kind of disease diabetes is and how it is treated, in order to self-manage the condition. Lastly, participants' stories were concerned with how they learned to live with the immediate and long-term bio-psycho-social impact diabetes had or could have on their lives. Although the structure was common there was not a straightforward temporal sequence to the stories, as the narratives were to some extent circuitous, continuous and open-ended.

Privileged and silenced stories

The most significant part of the plot was that the narratives were divided into things that were overtly told and things that were expressed in the accounts but not necessarily explained. Therefore, the narratives contained both privileged and silenced stories. The privileged stories told of the facts of their experiences and the things they did or found different in a life with diabetes. The silenced stories were often related to emotional elements within the narrative and were sometimes implied but not overtly spoken about in their encounters with health care professionals until these thoughts were elicited during the interviews. Hence, the privileged stories were the factual accounts of the events surrounding their diagnosis, while the silenced stories reflected their private thoughts and struggles in relation to adapting to a life with diabetes.

Therefore, the key feature of the plot was how these two story lines interrelated, one speaking of the facts and realities of the experience the other conveying the emotional and personal crises that ensued in response to those experiences.

The narrative structure itself expressed features of the adaptive process. It showed how key events and experiences can influence and shape this process. Their experiences of their life before the diagnosis, the events that took place following their diagnosis and, moreover, their thoughts and apprehensions about their future underpinned their narratives about adapting to a life with diabetes. Certain events in their stories moved very rapidly whereas at other times there was a sense of slow progression.

In addition, the narrative structure introduced some of the key characters that may be important to the participants in adapting to a life with diabetes. In their narratives, participants revealed that diabetes affected their interactions with significant others and compelled them to build relationships with health care professionals to maintain their well-being. Their narratives of adapting to a life with diabetes also featured issues of uncertainty. The participants' ongoing stories seemed to be less in their own control. In this sense the plotline was now being written by the course of diabetes and the demands it imposed on them. This story told how the participants found ways of reconstructing their lives in order to integrate diabetes into their everyday existence while adapting to the flux of a new life world. This included constant learning about the nature of diabetes and learning how to live with diabetes so they could accommodate it in their lives.

Section 2: The Diabetes story

The following section presents the main findings from the collective diabetes stories expressed within participants' narratives. Having outlined the narrative structure in the previous section, attention will now be given to the stories illuminating various experiences around the participants' diagnoses and the initial phase of adapting to their life with diabetes. Participants described how diabetes was enacted in multiple scenes in their home, their workplace/study and in the wider society. These scenes were often contrasted to their prior life situation as their role was changing due to the appearance of diabetes. The participants themselves were the protagonists in their stories with diabetes playing a main part. Other characters who played a part were their immediate family and friends, and their peripheral acquaintances. In addition to the familiar scenes and the people in them, new characters and scenes were introduced to participants' lives as they had to engage with the health care system and various health care professionals within it. Also on some occasions the general public became part of their narratives.

The underpinning plot line of their narratives involved their endeavours to understand and make sense of what had happened to them in order to establish coherence between their past, present and future life. In doing so they attempted to construct meaning in their experiences as they gradually realised what impact diabetes had on their physical health, their psychological well-being and their social world. There were variations in the bio-psycho-social effects of their diabetes and these influenced participants' perception of diabetes. In their narratives participants featured a multiplicity of cognitive, emotional, psychological and behavioural strategies they had to learn in order to move forward in their process of adapting to a life with diabetes. In this section the findings from the participants' narratives will elucidate the particular elements of the underlying bio-psycho-social phenomena that influenced their process of learning to adapt to a life with diabetes. In their narratives, participants illustrated their adaptive and learning processes as a series of interrelated events that took place during their initial experience of living with diabetes. These events were exemplified in a flux of interrelated episodes that were more often circuitous than linear. While there

were individual differences the collective narratives outlined two main learning processes that were essential for adapting to a life with diabetes. These processes highlighted how participants *learned about* diabetes and how they *learned to live with* diabetes. Learning *about* diabetes featured knowledge about the physical changes they experienced and the bio-medical aspects necessary to understand and treat the condition. Learning *to live with* diabetes featured the psycho-social aspects and changes that participants encountered and had to accommodate following their diagnosis. While these two processes were distinct they were also mutually dependent as participants' lives with diabetes unfolded. In the following section these processes influencing their adaptation to life with diabetes will be outlined individually, though it should be noted that they take place concurrently and cannot be separated.

Learning about diabetes

When reflecting on the early phase of adapting to their life with diabetes, participants identified that they had to learn about diabetes in the context of their experiences in their day-to-day lives. While this learning seemed to be phasic and multileveled it helped them construct a view of diabetes. Initially their main concern was learning about the nature of diabetes and the treatment of it with the technical skills they needed to self-manage their condition. When these skills had become an integral part of their day-to-day life, their focus shifted more toward the direct effects and potential consequences imposed by diabetes. Their initial learning about diabetes could not be done in solitude and mainly took place in health care settings participants were unfamiliar with. Likewise, the bio-medical terms and concepts related to living with diabetes that were used by the health care professionals were new to them. While most participants had some general knowledge about how their body functioned, only a few completely understood the role of insulin. Hence, they did not understand their initial symptoms and what consequences the insulin deficiency had for them. When they were introduced to a word such as hypoglycaemia it did not have any meaning to them because they had no prior experiences or knowledge to pin to this phenomenon. While health care professionals explained the potential symptoms, participants could only fully come to understand the meaning of those by experiencing an incidence of

hypoglycaemia themselves. Consequently, participants were dependent on the information they received as they constructed their view of diabetes. In essence, they were exposed to a vast amount of information that only made sense to them as they lived through a variety of new experiences within their existing settings. Moreover, adapting to life with diabetes was not just about acquiring information and knowledge, participants also had to change their understanding of familiar activities such as having a meal and doing exercise. Therefore, their theoretical or text book knowledge of diabetes had to be converted to a lived experience of diabetes. The various learning experiences that participants identified in their narratives in relation to learning about their diabetes are explained in more detail below.

Physical changes

The narratives relating to the physical aspects of diabetes were expressed in the context of their past, their present and their future lives. Describing the physical symptoms they experienced leading up to their diagnosis was a common way for participants to begin their story. The majority of participants reported having the usual symptoms of hyperglycaemia such as increased thirst, unintended weight loss or blurred vision, but without knowing these were compatible with the diabetes diagnosis. Therefore, most of them were very shocked when they learned they had diabetes. Some participants had been feeling physically unwell for a longer period but had been dismissive or put off going to their GP to find out what was wrong with them. One participant offered the following explanation to being reluctant: *"I was probably more like the kind of person who would say, 'Well, I don't have to do anything, I'll be fine soon' I usually am"* (Hans, forties, T1D 28 months). Another participant explained: *"I was really thirsty all the time and needed to pee and... my vision got worse. And it went on for a couple of weeks and then I thought... 'Well, I'll go to the GP just to be safe, and it probably isn't anything serious at all...'"* (Mie, twenties, T1D 19 months). Some participants attributed stressful life or working conditions as the cause of the physical symptoms they had experienced: *"I thought they were just symptoms of stress"* (Kurt, forties, T1D 32 months). Despite their symptoms most did not expect to

be suffering from a chronic disease and they knew little about diabetes, before they were diagnosed:

I didn't know anything really about diabetes, but I knew it was... serious but I didn't realise that it was that serious and so I thought 'Well, OK I'll probably go and get that checked out some time' and I was like 'OK, so what do we do now?' And she [the GP] said 'Well actually you need to go to hospital, you need to go to A & E' which I thought was... a bit of an exaggeration, I didn't expect that. So, at that point I realised it was serious. (Andy, twenties, T1D 15 months)

Although participants were shocked by their diagnosis, some expressed a sense of relief when they found out that their disparate symptoms were not fatal but caused by something particular that could be treated:

The previous months my body had felt more and more exhausted but without me knowing what was really going on. But after a few days at the hospital I could feel all the energy return to my body and suddenly I could walk a flight of stairs (...) Some things were positive because my body was feeling so much better. (Dan, twenties, T1D 31 months)

Some participants explicitly expressed they felt an initial alleviation when they found out they did not have cancer or a disease that would immediately disable them. A few participants were initially told they had type 2 diabetes and were treated with metformin. In these situations, the initial experience was confusing because the treatment did not help but even made them feel worse: *"I felt really bad after starting on Metformin and then I lost weight"* (Alice, sixties, T1D 33 months). Such experiences dented their trust in the health care professionals and made their transition into life with diabetes more challenging as the advice and information they had received initially was not valid or helpful.

Initial voices about the diagnosis and diabetes

Most participants and the people around them had limited knowledge about diabetes and its potential impact on their lives. Therefore, the initial voices about the diagnosis and diabetes were those of health care professionals. Participants agreed that what health care professionals said to them and the manner in which it was communicated in this early period shaped their understanding of diabetes and their adaptation to it. These communications had a strong influence on the overall process of adapting to life with diabetes. In some cases, this communication was not a positive experience. An extreme example of poor communication initially was a participant's meeting with a consultant while he was admitted to hospital following his diagnosis:

[A] consultant that I'd never seen before, and had not been introduced to me or anything, came and told me and I'm not exaggerating that I was going to have a heart attack when I was 50, I'd never be able to drive again, and I'd never be able to eat any chocolate or anything like that. Ever again. And I was pretty shocked, because I didn't know anything about diabetes and I'd just been diagnosed, and this guy had just told me this stuff. (John, thirties, T1D 31 months)

This way of representing diabetes and its potential impact without any kind of follow-up was an exception. In contrast to over-emphasising the potential risks of diabetes, most health care professionals portrayed the diabetes diagnosis as something that should not make a huge difference to people's lives and would not stop them from doing anything they wanted. Most participants initially found this approach more helpful and comforting, enabling them to continue with their lives, as illustrated by Adam (twenties, T1D 19 months), who wanted to carry on with his sports activities:

One particular consultant at the hospital... probably him to start with saying 'Look this isn't going to change anything. You can do whatever you want' was probably key and re-iterating that to me a few times going 'Look, you're not going to stop doing anything you want to do'. I didn't want to stop [running] and he goes 'We will find ways for you to do everything that you want to do' was probably the key thing.

The reassurance that it was possible to continue to pursue one's goals positively influenced participants' perception of diabetes and their engagement in learning more about it. However, the tendency of some health care professionals to downplay the seriousness and complexity of diabetes by saying it '*wasn't that bad*' and that diabetes '*just had to be managed*' had a flip-side. This type of reassurance deflated the significance for some participants to such a degree that they did not perceive diabetes as a major issue. This underplaying of the diabetes meant that some participants did not initially engage very much in self-management behaviours, and later became frustrated when they realised that their diabetes did need special attention, as one participant pointed out:

Stina: But, they [the health care professionals] have been very sweet and hugely supportive... and actually a little too much (P) [sighs]. You know, it is as if they unintentionally made it less bad than it should be; 'You can easily have a slice of cake you only need to take some extra insulin'. I don't think it's been made crystal clear how serious the consequences might be. They've almost comforted me to the point where they said, 'This disease is just..., we can easily...' you know, 'It's something that can be managed', you know?

Interviewer: And is it?

Stina: Well, that was the impression I got in the beginning. And that's why I wasn't as strict with my blood sugars when they've been around 12-13. But now I am. (Stina, thirties, T1D 16 months)

Participants found that disregarding the complexity of diabetes initially was unhelpful because their perception of diabetes had to change later on as they realised what diabetes could potentially mean to their life. Another unintended consequence of this dismissive reassurance was that it also acted to silence participants in respect of how it affected them emotionally. Being told that the disease was not too bad unintentionally conveyed the message that they should just get on with things, curtailing any expression of their anxieties.

I think, when you're first diagnosed, as well, there's this... because of the theory of diabetes; there's also this, well, I feel stupid that this feels so hard because... yeah, you almost feel like it feels a bit silly to say, 'This is really hard', because... what is hard about it? Kind of thing. It's hard to explain what is hard. Yeah...
(Jane, twenties, T1D 5 months)

The need for insulin

Following their diagnosis participants expressed an urgent need for basic information about how the insulin deficiency affected their body function and how this could be compensated for. There was a realisation that what was once an automatic system now required external management with insulin administration, this was expressed as an anxiety about a part of their body being broken and unreliable, leading to a feeling of powerlessness. One participant commented:

Suddenly I had this condition where I just, it was so personal, and I felt like (p) I knew it wasn't my fault but then again it kind of was my body's fault and if your own body can randomly attack itself I didn't really feel safe in a way. (Lisa, twenties, T1D 35 months)

Participants had to find ways to manage this insecurity about their body's fragility, as most of them were unaware about the details of diabetes and its treatment. Therefore, within their adaptation to diabetes they had to reconcile their frustration at the body's failure and the need to acquire the knowledge necessary for them to use insulin effectively. Participants also acknowledged that using insulin was not exclusively negative as it did make them feel better especially when they were first diagnosed, as illustrated in the comment below:

One of the things when I was first diagnosed I found was because I then had insulin. I felt sooo much better after I'd been given the insulin. I felt quite positive. (Jane twenties, T1D 5 months)

In the context of having to learn the skills necessary for using insulin, participants were aware that while insulin was good for them and necessary it also imposed

consequences on them, highlighting the potential fatal consequence if treatment was not initiated and adhered to. One participant compared the uniqueness of her experience to other issues she had to deal with before:

This was something, there was a way of dealing with it but there was no choice about it and that I think was the driving factor. That was the reason why it was different. This way or the highway. This way or die. (Amy, twenties, T1D 38 months)

Participants were well aware of the significance of insulin and, moreover, they recognised that this form of treatment had not always been available for people in the same situation. One participant contrasted his chances now with those he would have had a century ago:

Well, I know [insulin] is my friend because if I didn't have it I would've been dead by now. A hundred years ago you would die from diabetes. (Kaj, sixties, T1D 23 months)

However, a few participants tested the boundaries of their diabetes by trying to avoid taking insulin by either having very little to eat or doing excessive exercise but quickly found that such approaches were unsuccessful and unsustainable.

It was in the context of these reflections that participants took up the task of learning the technical skills around blood glucose measurement and insulin injections. In essence, they now had to take over a new role to compensate for the failure of their bodies, it was now their conscious responsibility to continuously manage this complex task.

Technical self-management skills

An important experience for the participants in adapting to their life with diabetes was to learn the basic technical skills of diabetes self-management. They felt some pressure to acquire these skills quickly to enable them to self-manage their condition so they could be discharged from the hospital scene. This involved not only acquiring the skills

but also adapting them, so they could negotiate their diabetes in the context of the more familiar scenes that defined their everyday life at home and in their work places. In doing this they had to master the use of peculiar devices they had never come across before such as insulin pens, needles and blood glucose meters. These odd devices had to be integrated into their familiar lives to be used before doing normal things like having a meal or driving. While the participants were aware of the urgency of learning how to perform self-management, they were still overwhelmed by fearful emotions and some felt they had to overcome significant barriers in using their new treatment devices. They also realised that using these devices was quite complex as their insulin requirements were not fixed and had to be adjusted in relation to other factors such as food intake, activity and their glucose level. Many felt overloaded and anxious in having to develop their skills and in processing all the information needed to make effective decisions. The comment below illustrates the dilemma between their anxieties and the pressing need to learn new abilities:

The thing with having to... I couldn't take it in at all... And I'm still not fond of needles. To have to try to prick the finger and just like, 'Wow, this will never work'. The first time I felt like fainting; I needed to inject the insulin in the stomach and... it was, yeah, pretty surreal to try to get used to those things.
(Mie, twenties, T1D 19 months)

Participants emphasised that they were forced to face the changes that were imposed on them without having any time for preparation. Commenting on this one participant said:

She [the DNS] sat me down and, yeah, we just went through it. It was a lot. Like, it was a lot to take on board, and... yeah, I mean, it wasn't... it's not the kind of thing you ease yourself into. I mean, you have to start doing it right away. (John, thirties, T1D 31 months)

In adapting to these new circumstances some participants compensated by building routines around their management of diabetes and tried to develop automated actions in relation to the blood testing and insulin injections. However, although they adopted

these behaviours and recognised the benefits in so doing, they also felt that this was tiresome and demanding. Commenting on the daily demands of diabetes, one participant said:

But the thing with... having diabetes, it's not like... You know, all in all, things are going well, and I know what to do but it's just hard. You know it's really tedious. Measuring blood sugar and taking insulin four times every day. I think it's such a bother having to do that. (Mie, twenties, T1D 19 months)

Conversely, for others the basic mechanics of self-management such as blood testing and injecting insulin were perceived more as a minor part of learning about diabetes. Rather, it was the time-consuming effort and the complexity of interpreting the information that was available and applying this to their management in the context of their day-to-day choices they perceived as exhausting:

I mean testing your blood takes about ten seconds; injecting yourself is click click click jab 20 seconds later take it out get rid of the stuff, you know. So the actual physical act of taking the medication and some testing is very short. But it's things like 'Oh let's look on a menu, ok chicken, sweet and sour chicken well I'm not going to have that because it's probably got a lot of sugar in,' or reading the labels on stuff takes a lot longer than that, you know. It's the associated things that take a lot more of your time and again the internal dialogue 'Oh can I do this, can I do that?' (Bob, twenties, T1D 13 months)

As illustrated by the comment above, mastering their devices by measuring blood glucose and injecting insulin correctly was only one part of managing their diabetes. For many the greatest challenge and source of negative emotions was the more complicated equation of balancing food, physical activity, and insulin to maintain a near normal blood glucose. Although mixed messages about the management of diabetes were prevalent, most participants reported that health care professionals placed a massive focus on getting their blood glucose levels down as a priority immediately following the diagnosis. It was stressed to them that their blood glucose levels were to be as close to the normal range as possible. In order to do that participants needed to understand how different foods and activities influenced their blood glucose. They had to pay attention to their choice of food and their levels of activity in the context of their

insulin treatment. This was in sharp contrast to their previous lives where they did not have to give this much thought. In their narratives participants explicitly made reference to how mundane activities like having a meal or going shopping suddenly became very complex. While some participants did pay attention to their food choices before the diagnosis, their reason for doing so was to improve their general health in the long term, rather than as a daily necessity. A variety of perspectives were expressed by the participants regarding their increased attention to food and the quality of the guidance they received relating to this. Some participants referred to getting specific advice as being helpful in making changes to how they organised their food intake and in understanding how the different constituents of their food affected their blood glucose:

They said 'Don't drink any fizzy, soft drinks that are not diet, don't drink any apple, you know, fruit juice, whatever, you know, always look out for the sugar', gave me quite a good sort of, like, crib sheet on what I really shouldn't be doing and what I should be doing, which made it really easy to, sort of, pick what I was going to eat... just focus on getting my numbers down and eating at the right times, because I was missing breakfast and having a big lunch and then, you know, before. So it was a big change for me to eat breakfast, lunch, dinner, breakfast, lunch, dinner, breakfast, lunch, dinner. So, yeah, the information they gave me was pretty good. (Bob, twenties, T1D 13 months)

Others, however, were more frustrated by the advice they were given by health care professionals and found it useless in their endeavour to maintain a stable blood glucose, as one participant emphasised:

*What they say is, 'Just eat normally. You'll be fine. You can do this.' **No you can't!** It's a load of crap. It is a load of crap. This whole thing about telling people, when they've got [diabetes] 'Oh, you can eat normally.' No you can't. (Jack, thirties, T1D 4 months)*

The difficulty of balancing food intake, activity level and insulin to achieve a level blood glucose was echoed by several participants. Participants had to be able to understand the principles around carbohydrates, and in addition, they had to have a high level of numeracy to enable them to calculate their insulin doses. A few participants expressed

concerns about their ability to match these requirements and they were worried about how that could affect their health. After taking part in structured education and realising the complexity of balancing insulin doses with food and activities one participant remarked:

If this is a numbers game, that's what this disease is about, I'm probably not as confident that I'm going to be in the forefront and winning as I thought I would be. If it is a numbers game, if they're talking about good management is to calculate and cut literally down to the finest detail of what you're eating if you can master that the better you're going to do. I did question myself thinking, 'Well, maybe' the same feeling I used to get in Maths class at school. (Sue, twenties, T1D 4 months)

There were variations in the way in which participants made adjustments around their food. Some felt that sticking to the same types of food were helpful and made their insulin treatment easier, but they also felt somewhat restricted and were challenged in situations where they had less control, such as when having dinner outside of their own home. Others chose a less strict approach to their choice of food, but would sometimes refrain from eating cakes and other items containing a high amount of carbohydrates because they felt it was difficult to adjust their insulin adequately. A few participants made a decision to completely alter their eating habits and followed a low carbohydrate high fat diet. With the increased public focus on various types of diets and food allergies, some participants felt that their particular food choices were not questioned or considered negatively by others. Although health care professionals did not recommend the low carbohydrate high fat diet; participants reported that this change in their diet paved the way for more stable blood glucose values and fewer incidences of hypoglycaemia.

A while after their diagnosis some participants were introduced to more advanced technical devices that could assist them in their self-management and help keep their blood glucose within a certain range. Some participants had rapidly developed

impaired hypoglycaemia awareness and were offered continuous glucose monitors (CGM) to try and prevent them from having episodes of hypoglycaemia. They then had to learn how to handle this new device and to interpret the additional information that now became available to them. They found the CGM was a huge help and also gave them a feeling of security, although they were aware of its limitations, as one participant explained:

Before... I was always afraid, 'Is my blood glucose low? Is it high?' But I don't have to think about that now because it [the CGM] will let me know when it's low. That's a great relief because otherwise you have to be vigilant all the time. Well, I still need to be somewhat alert because it [the result] is delayed. (Alice, sixties, T1D 33 months)

In addition to the CGM a few participants were offered an insulin pump to further reduce their risk of hypoglycaemia or as a way of increasing their flexibility in relation to food and activities such as work-related tasks. Others were offered the insulin pump to help them lower their HbA1c or have more stable blood glucose values. Some participants requested an insulin pump themselves. Again, this new device meant that they had to learn new technical routines around their self-management of diabetes. It also illustrated how over time the participants became more aware of what technologies were available. They showed some interest in using more advanced technology if it improved their ability to manage their diabetes and made their life with diabetes more straightforward.

In summary, the process of adaptation in relation to developing self-management practices following diagnosis was multifaceted and time consuming and it was persistent over the course of their narratives. Participants had to learn complex skills they could apply in a wide range of day-to-day situations. They had no choice but to take on this task instantly while still feeling fragile and overwhelmed by the diagnosis.

Encountering hypoglycaemia

The risk of hypoglycaemia was another new experience for the participants. Concerns regarding hypoglycaemia were widespread among the participants, as they all had experiences thereof. They described the physical and cognitive symptoms they experienced, such as sweating, rapid heartbeat, blurred vision, loss of concentration and being emotionally volatile, as unpleasant and extremely disturbing to their daily rhythm of life. This affected their ordinary activities. They were concerned with the potentially devastating consequences for their well-being and for their ability to take care of themselves unless they managed to plan ahead or have the necessary remedies available to compensate for a falling glucose level. For example, one participant referred to a situation when an imbalance between activities, food and insulin had a significant impact on himself and his fiancée:

The worst hypoglycaemia I had, which was really scary, is about April time, and I did a lot of exercise that day. I went to the gym, I played football in the evening and then I had sex with my girlfriend later that night, and that was a lot of exercise without having much food. And I woke up in the middle of the night, about 1am, tested my sugars, and I was 1.9. And I went to the... I was... I don't like waking Sara up... I let her sleep and I went to the kitchen to have some sugar and deal with it. But I was so low... I was the lowest I've ever been... that I wasn't with it and I was staggering to the kitchen and I couldn't find anything with sugar in it. So I just grabbed anything. I grabbed yoghurt and I started eating it but it wasn't having any effect. And I hate asking... I didn't want to ask for help, because it was 1am in the morning. I didn't want to scare Sara. But it got to the point where I was in such trouble that I had to crawl from the kitchen to the... I live in a one-story flat. I crawled from the kitchen to my bedroom and I had to wake Sara up by holding onto her foot and saying, 'Help.' And I was sweating, but I was also really cold, and she was like, 'What's going on?' And I was like... 'cause she was obviously delirious. It was, you know, 1am in the morning and she hadn't woken up properly. And I was like, 'I need help. I need sugar.' She finally realised what I was going on about after two seconds, and ran to the kitchen and she just got some honey and just... I couldn't hold it, I was so out of

it, and she had to squeeze it in my mouth, and I was there... I was sweating, and I was crying, and I was... yeah, it was awful. And she was obviously really upset because she hadn't seen me like that before. I never want her to see me that bad. I always promised it'd never happen... And after 15 minutes, I was fine. I was, you know, obviously a bit of a mess and a bit emotional but that was... that was the worst it's ever been, and it's never happened again. I said to her it would never happen again. But... yeah, that wasn't fun. That was quite difficult. (Bill, twenties, T1D 46 months)

Other participants had similar intense experiences with hypoglycaemia in the early phases of diabetes. For some, their initial experiences of hypoglycaemia instilled a fear in them so that they would take any measure possible to avoid such incidences. Concerns were also expressed about becoming hypoglycaemia unaware. One participant offered her concern about this and her fear of hypoglycaemia as explanations for keeping her blood glucose levels high for a long period of time following a severe hypoglycaemia:

I was terrified of hypos and I still am. And I kept my blood levels higher and higher and then I got into that bad routine and I'm still there (...) Now I think it's more a behavioural thing and I think it's, I'm just so scared, I just hate the feeling so much (...) And so to have to keep thinking about whether I'm having a hypo or not is annoying. And hypo-unawareness is what I'm most scared of I think. So to keep my levels up makes me think I won't get hypo-unawareness but (P) I don't know. (Amy, twenties, T1D 38 months)

Contrarily, other participants were more concerned about future consequences of high blood glucose levels and therefore, they were more likely to experience hypoglycaemia. While most participants reported that having a hypoglycaemic episode was very uncomfortable and disturbing for their day-to-day activities, some were more focused on preventing the long-term consequences of high values rather than the short term consequences of low blood glucose values. When reflecting upon his perception of having hypoglycaemia and his thoughts and behaviours related to his management of blood glucose values, Mark (thirties, T1D 28 months) said:

Mark: [There's the] fear of being so unwell that I can't do anything myself, because I have tried that a few times. I haven't passed out as such yet where I needed an injection but lots of times others have had to feed me and that's not a great feeling at all. It's rather humiliating.

Interviewer: So, what do you do to prevent that?

Mark: Eh, nothing really. Actually, I'm doing the opposite because I often put pressure on myself.

Therefore, anxieties about hypoglycaemia were formed very early in the disease experience and these could result in compensating adaptive behaviours that could become rapidly habituated.

The fear and frustration of hyperglycaemia

Participants were often concerned when their blood glucose levels were elevated. While they were mainly able to identify the cause when their blood glucose was high, this was not always the case. Many felt frustrated by seeing unexpectedly high values, sometimes interpreting the result as a sign of personal failure. This frustration led some to potentially unhelpful adaptive behaviours, such as refraining from measuring their blood glucose. The motivation for this behaviour was not only to reduce their sense of frustration at seeing an elevated reading, it was also used to conceal the high numbers from health care professionals at their next consultation. While they were aware that this was an unaccommodating way of taking action, they felt disinclined to show their real values to health care professionals to avoid their judgement. These conflicting feelings were expressed by Stina (thirties, T1D 16 months):

Stina: If I have a feeling that my blood glucose is too high I'll take some insulin before I measure it [giggles] because otherwise he [the doctor] can see on my meter that it's too high. I'm embarrassed if it shows that it is that high although it might have been, you know? So yes, it stresses me a bit that he can offload the values in my meter... and expose me if I have been naughty.

Interviewer: Naughty?

Stina: Yes, but it's not intentional when it happens. Sometimes you think 'Oops how did that happen? I went to bed at 8 and wake up at 16 and I've just been sleeping?'

The participants who adopted this approach were aware that it may affect their communication with the health care professionals, hampering the possibility of learning more about how to better manage their diabetes.

Running high glucose levels was not without its consequences. When participants described their experience of having hyperglycaemia, many reported being short tempered and more likely to feel depressed which could negatively impact their interactions with others. In addition to the short-term after-effects of hyperglycaemia, concerns regarding the long-term consequences of high blood glucose were also expressed by the participants, again leading to negative thoughts. These concerns were related to the fear of developing physical complications but also worries about having a shorter life expectancy than people without diabetes and potential effects on having a family:

Then you think about what might happen if I have children one day. And then you think about... I don't know... what happens if I don't control everything well and I go blind? Like, all those things. So, I think that the actual day-to-day stuff has been a lot easier to deal with than the speculating about what might happen. I feel like the future worries part is a lot worse for me than the actual... happening part. (Helen, twenties, T1D 32 months)

Therefore, participants experienced hyperglycaemia as a disruption to their physical state and it generated a sense of failure and frustration that had a negative impact on their mental well-being. Moreover, high glucose values caused further distress as participants were concerned that they would potentially compromise their health and well-being long term.

Keeping blood glucose levels within range

Another feature of learning about diabetes that had an impact on the adaptive process related to observing and maintaining their glucose levels in the range that would lead to good diabetes health. These ranges were externally prescribed by health care professionals and failure to attain them could drive anxiety and frustration. Most participants were striving to maintain a glucose level between 4 and 9 mmol/l, according to the advice they had received from health care professionals. When contrasting high and low levels of blood glucose the majority of participants preferred lower levels despite the associated risk of hypoglycaemia. In some of these cases, participants' awareness of hypoglycaemia had become impaired as a consequence of striving for normal values. It was, however, extremely challenging for most of them to maintain the glucose levels in the target range at all times. While participants identified the various factors that influenced their blood glucose levels and made an effort to manage these, they were not always able to control them. They perceived that from time to time their diabetes seemed to have a life of its own. This unpredictability was extremely distressing for the participants because occasionally their endeavours seemed hopeless, creating a sense of failure. Commenting on her experience of the volatile nature of diabetes and contrasting her effort with her gain, one participant said:

*Well, it turns out I cannot control it. Two and two actually doesn't add up to four... It doesn't work that way. And it's just... It is **extremely** frustrating for me that I can't manage it properly. (Alice, sixties, T1D 33 months)*

The complexity of adapting to life with diabetes was evident in the participants' endeavours to negotiate their self-management behaviours around their blood glucose levels. This created a dilemma for the participants. While on the one-hand they were told that to be safe they should achieve these targets, on the other their experiences told them that blood glucose levels are unpredictable and hence they felt a constant sense of failure.

Negotiating stress and illness

In addition to the routine aspects of their day-to-day lives such as their food and activity, diabetes meant that they also had to learn to navigate their life with diabetes in circumstances that were less common such as stressful situations and times of illness. While food intake and level of activity to a large degree could be planned and managed by participants, exposure to stress in general or contracting a viral illness were more unpredictable and uncontrollable. Participants expressed concerns about their ability to manage their diabetes when falling ill with an acute illness. They had received information about sick-day rules from health care professionals but worried about their ability to manage their diabetes and apply these rules while feeling unwell:

There are things I haven't tried out yet which I don't know how I will react to. Actually, I'm truly afraid of falling ill. Because I've heard that I would need more insulin. (Pia, forties, T1D 9 months)

While most participants were given some information about the potential impact of stressful events, there were individual differences in how these were experienced and how they affected their blood glucose levels. When relating her experiences of stress one participant said:

I remember that my sugar was fine, and then I had a customer at work who gave me... [sighs]... a headache. For about 20 minutes, I was serving her. And my blood sugar, I think I was at, like, 6.8, and I dropped to, like, 4 within that 20 minutes and I hadn't eaten anything or drank anything or been walking around or doing high exercise. Stress! Stress! It... within, like, you know, minutes it can drop it. (Sue, twenties, T1D 4 months)

Therefore, in addition to learning facts about diabetes that could be applied in their day-to-day lives participants had to be equipped to manage events that were less predictable. While theoretically being somewhat prepared for managing their diabetes in uncontrollable situations such as acute illness and stressing events, participants

again had to experience these incidences in order to fully apply their knowledge and gain understanding from their experiential learning.

The honeymoon period

A significant aspect in the participants' narratives in learning about their diabetes was the flux of their honeymoon period. During this time some of the learning they had internalised initially had to be modified as their insulin secretion levels varied within a limited time frame. While most participants were informed about the benefits of the honeymoon period in relation to insulin management, they felt frustrated by the unpredictability of its onset and duration. Despite insulin management being simpler during the honeymoon, many were concerned throughout this period about what would happen in relation to their management of diabetes afterwards. Indeed, most participants expressed a desire for the honeymoon to come to an end so that they could understand the full extent of what diabetes would demand of them. As one participant put it:

I'd been told by numerous health professionals, dietitians, nurses, consultants that it would end. The only thing that I couldn't really get a proper consistent answer from them all on was how long it would probably last and I'm still not sure. So like I think there's still a very small chance that I am honeymooning slightly now, which would be unlikely because it's almost two years, but not impossible and some consultants have said, you know, 'I've known it go on for three years in some patients'. One consultant said 'Well, you know looking at the doses and how your doses have changed it would seem unlikely that you're still honeymooning just because they've risen as much as they have'. So that's kind of frustrating, not knowing when it's going to stop and when you're going to plateau in terms of your medication and your behaviour and stuff like that. But in the meantime, again it's a case of 'Oh is it happening now?' and you know it's kind of like waiting for your waters to break or something like that. (Andy, twenties, T1D 15 months)

Some participants expressed reluctance in reducing their basal insulin as they entered their honeymoon, due to their fear of hyperglycaemia and the underlying threat of complications later on resulting in long periods with recurrent hypoglycaemia. The random time span and progression of the honeymoon was reflected in the participants' accounts. Many had paused or reduced their insulin dose for a period of one year or more. Two participants had not taken insulin regularly for about three years. While they were aware of diabetes during their honeymoon period and conscious that it would end at some point, they did not feel prepared for the changes in management this involved. One participant highlighted that when his honeymoon period ended it was almost comparable to the disruption he felt when he was first diagnosed because of the demand for significant self-management adjustments in his day-to-day life. This change heightened his need to learn more about diabetes in order to adapt to this new situation:

Bill: And then when I came to ending my honeymoon period, about November/December last year, it was like I was nearly diagnosed again, because I... then... 'cause this was now permanent. So, my understanding about it had to develop once more and I had to be a proper diabetic as... you know, just...

Interviewer: A proper diabetic?

Bill: Yeah, rather than being a type 1 and a half, as it were. So...

Interviewer: Is that your own expression, or did somebody

Bill: Yeah, that's my expression.

Interviewer: OK, yeah.

Bill: Yeah, that's a... 'cause before, all I did is watch what I eat and exercise and I knew that... I knew, based on testing myself to start with and testing myself every so often, that that would be enough. I couldn't go excessive on anything, but that's fine. I never did anyway. So I did maintain a relatively healthy lifestyle. And that was enough, but when I got back on insulin, everything had to get tighter and I had to learn a lot more very quickly. I had to (p) understand the complications with my eyes, my feet, and all the complications about having too high or too low blood sugar came into it. (Bill, twenties, T1D 46 months)

Constructing a view of diabetes

In summary, the multifaceted process of learning about diabetes aided the participants in constructing a view of diabetes and the impact it may have on their lives. Participants identified learning about diabetes as a complex and continuous process throughout their initial phase of living with diabetes. The complexity was evident in the multifaceted knowledge-base they needed to acquire for understanding and adapting to their diabetes. Building this knowledge-base assisted them in expanding their cognitive and behavioural strategies by learning completely new competences such as insulin injection as well as novel approaches to mundane activities such as going for a walk. Their knowledge and understanding of diabetes influenced how they build those skills and how they made use of them. While these newly acquired skills were taught by health care professionals in the hospital settings, the participants were compelled to integrate the application of them in their everyday life. Therefore, learning about diabetes required time and exposure to various familiar and unfamiliar situations in which the participants gradually integrated their experiences. Participants identified a change in their perception of life and areas where their social roles were altered as a consequence of having diabetes. Therefore, in time, the focus of their learning expanded from the technical skills and self-management to learning how to live with diabetes.

Learning to live with diabetes

Following their diagnosis participants had to face living with a chronic condition for the rest of their lives; a new situation over which they had no choice and that they could neither change nor reverse. Therefore, they had to reconstruct their lives to accommodate diabetes while building on past experiences and their new knowledge about diabetes. This reconstruction involved having to adjust their view of themselves and construct a new identity as a person with diabetes. In doing so they needed to combine their past experiences and aspirations with their new situation and future goals. In essence, they were now in the process of learning to live with diabetes.

This second phase of learning seemed to be much referenced with concerns about the threat diabetes presented to their daily experiences and their future health and well-being. It also integrated with their past life reflections, their perception of diabetes and the psychological resources and adaptive strategies they employed. For example, one participant contrasted his previous life experience to his present situation and how he needed to learn new ways of thinking about his day-to-day life:

*[It's different because of] having a chronic disease you just know can't be healed, cured or anything. So starting out by finding out about all the practical things, like taking the right insulin, eating the right things and figuring out how much exercise you need to do on a daily basis etc. By and large I've figured that out by now. So now it's more this idea of having to think about diabetes **all the time**, after having lived 40 years without... this abrupt change from having a normal life, as you say, to having a life where you really have to be in control of yourself, which I wasn't before at all. That really demands a strong backbone.*
(Hans, forties, T1D 28 months)

Having illustrated the physiological changes and the practical adjustments participants had to make in their day-to-day lives in the last section, the following section contextualises the participants' narratives about diabetes in their personal life and their social settings. These narratives capture the impact of diabetes on all aspects of their lives and how they seek to find ways to integrate diabetes within their sense of self and their social world. Commenting on the complexity of his new situation, one participant said:

It's quite easy to learn how functional, how it works with insulin and everything but what's hard is the mental [part] to learn to live with it in your brain and with yourself and accept it and I think this is the most important part. (Tony, twenties, T1D 5 months)

Emotional responses

Participants identified their emotional responses following their diabetes diagnosis as significant components of their process of adapting to life with diabetes. When participants reflected on their diagnosis of diabetes, they identified it as being completely different to any previous life challenges they had encountered. In this sense they perceived diabetes as having had a unique impact on their life. While this view was common to all participants, the way it was expressed was contextual to their prior life experiences, which were personal to each individual and the amount of life they had lived. Participants in their twenties related the experience to other significant life stressors associated with young adult life. It was perceived as a particular thing to deal with among the many transitions and events that occur during this period, as illustrated by this quote from Nick (twenties, T1D 17 months):

I think the feeling I had in those... that initial sort of part of the diagnosis was a lot more overwhelming than anything else I'd felt. I spoke earlier about, like, you know, university deadlines and stuff like that, and about worrying about stuff like that, but it was in a completely different league, really.

For the older participants the diabetes diagnosis was expressed more as an intrusion on their established lives which was totally unanticipated, as expressed in these quotes from Hans (forties, T1D 28 months) and Kaj (sixties, T1D 23 months):

You've had a normal life for such a long time and then your life is completely changed. (Hans)

I dare say it was the biggest punch in the gut that I've experienced so far. I was more than 60 years old when I got it... I have never been really sick before so it completely knocked me off my feet and now two years after it happened it still does. I'm still licking my wounds. (Kaj)

Following the diagnosis participants expressed their emotions in relation to diabetes. They spoke about emotional responses such as grief over their lost life, anger, anxieties and uncertainty about the future, fear of the unknown and feeling overcome. Although the majority of participants knew little about diabetes initially, they felt overwhelmed

by the prospect of living with a chronic condition. Within a very short time span they had to absorb a multitude of information about the disease while they were wrestling with questions about its cause and pondering over what consequences it might have for their future life. One participant said:

I started crying, I was really, really... first of all I was really frustrated, I told myself 'Why me, why now?', because I was just about to graduate my Master's and start working and it was the worst timing ever. So I got really, really sad.
(Tony, twenties, T1D 5 months)

Another participant commented:

Actually, I was just sad... I cried... when I saw it [the blood glucose reading] was 30 (...) I was grappling with it and I was really sad then (...) I cried and I tried to call my girlfriend. I was miserable. (Emil, twenties, T1D 3 months)

When reflecting on the impact on their lives, participants defined the uniqueness of their diabetes in terms of its enduring nature, in contrast to their previous experiences with illness which had been temporary and curable. For example, one participant voiced his changed perception of illness in the context of previous sports injuries:

Probably don't think I'm as invincible as I used to be (p). Certainly, I played sport all my life and I've broken everything, been put in comas, I've been seriously hurt, had a lot of injuries but I've always bounced back and come back stronger, nothing seems to have slowed me down, but this is certainly something that (p) there's no matter how long of rehab I do, how much rehab, [nothing] is going to resolve it. (Adam, twenties, T1D 19 months)

Another participant contrasted her experience of being treated for breast cancer which was limited in time to the enduring nature of diabetes:

I needed to have surgery, chemo and radiation treatment. But then I was done with it. It was over. With this [diabetes] you have to learn to live with it. It's for the rest of your life. Actually, that was probably the hardest part to accept.
(Lene, sixties, T1D 34 months)

The issue of time and their altered illness experience meant that participants had to find different forms of expression in constructing the meaning of diabetes in the context of their personal health and their future life.

Existential reflections

The emotional response to diabetes generated deeper personal questions for some participants, as they searched for an explanation as to why they had developed diabetes. Although most participants did not have any prior knowledge about the cause of diabetes, there was an overall sense of resentment that they had not done anything to deserve it as they made reference to having lived a healthy lifestyle before receiving the diagnosis. Therefore, they felt it was unreasonable that something like this was imposed on them. This view was prevalent across the age span. A younger participant stated:

I feel it's so unfair because I had done all the right things not to get diabetes and then I actually got it. (Jonas, twenties, T1D 24 months)

Another participant, who was older, said:

I was diagnosed with diabetes. It was a punch in the gut. I didn't feel I deserved that. (Kaj, sixties, T1D 23 months)

Whereas most participants felt resentful, for some, the main emotion was guilt, where they actually thought that maybe somehow they had brought diabetes upon themselves. While this perception would seem irrational as they had no control over the development of their diabetes, some suggested that such feelings were an obstacle in their process of adapting to diabetes:

I think at the beginning I struggled (...) because I had a level of shame and I didn't really understand why it had happened and without understanding why something happens I think it's harder for you to process and it's harder for you to accept. (Lisa, twenties, T1D 35 months)

When participants challenged the health care professionals to provide enlightenment about the cause of diabetes, the answer was typically that no certain pathophysiological explanation for why people develop type 1 diabetes was available. Although participants were reassured that they could not have done anything to prevent diabetes and that they were not to blame, they still grappled with these existential thoughts while trying to make sense of what was happening to them and find meaning in their chaotic situation. In some cases, health care professionals implied that diabetes could be triggered by stressful life events that happened before their diagnosis. A number of the participants had experienced traumatic events such as a relationship breakup, bereavement or high work load prior to their diagnosis, and wondered whether these were catalysts for them developing diabetes.

While the health care professionals directed the participants not to spend time wondering about the cause of their diabetes, they continued to be preoccupied with existential thoughts for a long time following their diagnosis. Health care professionals often failed to acknowledge or respond to these beliefs and feelings, despite their importance for the participants. One participant recalled:

Kurt: I was told that I shouldn't worry about the reason I had diabetes because they weren't able to figure that out.

Interviewer: How did you feel about getting that information?

Kurt: It meant a lot. However, although they told me that, I still thought a great deal about why. I thought I did what I could to live a healthy life. Well, of course I could have done more but yeah, I didn't expect that at all. (Kurt, forties, T1D 38 months)

Therefore, while the participants were grappling with these existential thoughts continuously during their process of adapting to a life with diabetes, these thoughts were silenced in their interactions with health care professionals and remained unresolved.

Loss

Many of the narratives expressed a sense of loss as a consequence of developing diabetes. This loss was multifaceted and reflected: physical loss, the loss associated with their changed metabolic functioning – a loss of a normal body; loss in the context of their freedom to make everyday choices without any immediate consequence; and loss related to their futures as they assessed the potential serious impact of diabetes on their lives unless they behaved in a certain way. Some participants felt constrained and overwhelmed by this, as illustrated by Pia (forties, T1D 9 months):

I felt trapped. So, eh... my freedom! I couldn't just do whatever I felt like doing.

There was a sense in some participants of having lost their prior life allied with feelings of uncertainty as to what the future would hold. There was also a sense of anger as diabetes changed everything about their old lives, as illustrated by the following comment:

So, your whole life... they don't tell you that. 'Oh, by the way. The life you knew has gone out the fecking window. Say goodbye now cause it's gone.' (Jack, thirties, T1D 4 months)

While some participants featured the loss of their 'carefree' life before diabetes, others spoke about losing their future aspirations. A few participants expressed concern about the risk of passing diabetes on to a child, and therefore, considered not having children. One participant, who had long been aiming for a career in the military or the police force had to give up his dream. When comparing to the hassles of managing diabetes, he felt that letting go of his dream was a much bigger obstacle:

I'm never really annoyed by the diabetes because I don't find it difficult... when it comes down to it, it's all the things I'm not able to become that are the most annoying part. That's what takes up a lot of thought. Although I've given that [becoming a police officer] up I'll probably always think about it. But I'll have to work something out, you know. I'm not... I'm finding it difficult to work out what to do now. (Jonas, twenties, T1D 24 months)

Separating the management of diabetes and learning to live with the consequences thereof was echoed by another participant. She, too, spoke about her line of work, but her concern was losing her family business as a consequence of having diabetes. She had to perform hard manual labour to maintain her business but found balancing her work and her food intake with her insulin dose extremely difficult and she experienced many hypoglycaemias. The comment below illustrates her struggle:

Well, I don't have a relationship to the disease as such. It's the limitations it imposes on me I can't accept (...) the fact that I can't perform to the degree I would like to. (Alice, sixties, T1D 33 months)

Participants contrasted the demands of their new life with diabetes to their former life in which they were able to do things impulsively and without giving much consideration to what would happen next. Previously there would not be any immediate consequences for their physical wellbeing if they decided to engage in various activities or not. However, the flexibility of making small or large instant changes to their plans was now lost. In order to continue to take part in normal activities they had to engage in unusual measures to make that happen. The comment below illustrated how diabetes may influence day-to-day living and highlighted areas where participants needed to learn new ways of engaging:

On the one hand they say, 'You'll live a normal life,' and that's absolutely true. I can basically do everything except join the army, but on the other hand it affects everything. So it affects my work, I'm always checking my blood sugar at work, I'm always wondering in a meeting whether or not I'm high or low and I can't play a game of football, run for the bus, have sex, get drunk, fall asleep in front of a movie. There are a lot of spontaneous things that I've taken for granted my whole life that suddenly I can't do without at least giving a little bit of preparation for and that's a big change for someone in their; I was 25 when I got it, in their mid-twenties, when stuff is meant to be like fun and carefree, that's a big change. (Andy, twenties, T1D 15 months)

This view was mirrored by another participant who was in his sixties when he was diagnosed. He found that diabetes needed constant attention and disrupted his normal routines:

*These are things [travelling and flying] I have done before without thinking about it. I've done that my whole life. And then suddenly not being able to do them [without additional planning]... I feel that is a **huge, huge** infringement.*
(Kaj, sixties, T1D 23 months)

Participants expressed feelings of anger and resentment in relation to the perceived constraints diabetes introduced to their lives. For some this triggered acts of defiance, with occasional negative impact on their approach to managing diabetes. When relating his experience, Tony (twenties), who was diagnosed five months prior to the interview, described his inner battle:

*Tony: There are a lot of hard and tough things, for example it's not positive every time and I can go into some moments, some periods when I just hate it [diabetes]. I'm **so** tired of it and that's usually when I'm either at work or I'm with friends, I'm with people who don't need to think about their behaviour. So, for instance, there are some times when I forget to check my blood and when I remember, 'Oh I forgot to take it, oh why should I take it, I don't need to take it, I can still survive, they don't take it, why should I take it?' You know, you're still fighting with your brain sometimes, you're out with friends, you're having a beer and you say 'Maybe I shouldn't have a beer, like it's not good for my blood, do I need to check it, check it, come on'. So sometimes I go to like some... it's quite weird, some denial stage for a few hours.*

Interviewer: It's quite weird you said?

Tony: Yeah because...

Interviewer: Do you think it's weird?

Tony: No. It absolutely makes sense but it's just... I'm just fascinated with the brain because usually I have so much structure in my brain, I'm a diabetic, and then just sometimes now and then I can just completely lose track, well not

track, my brain is getting lazy, it's getting distracted and I go into these behaviours, 'Maybe I should, maybe I shouldn't', and the brain starts to try to convince you to do it, but after a while it says 'Come on, Tony, wake the fuck up and just take it', you know, but it's really tough, at least in the beginning before I learned everything, I had to fight a lot with it.

These negative thinking processes seemed to be quite enduring as they were evident in those who had diabetes a little longer and at the follow-up interviews. Although these feelings became a little less intense they were intermittent reflecting the peaks and troughs of how difficult they perceived their life with diabetes to be. In this sense, the physical and emotional adaptation was ongoing throughout the first three years. While participants indicated that time and experience were conducive for integrating diabetes into their daily schedules, they did not cease to consider it an inconvenience in their lives as expressed by one participant:

This is something that demands a lot of time, I think (P). And also, subconsciously you know, I feel it's subconsciously in the back of my head all the time. You are reminded all the time, that now you need to do this and now you need to be careful with that, now you need to measure blood sugar and things like that. Of course, the longer one has had it it's like I notice that it becomes more and more like a routine. But still having to do these things; like with work, one needs to consider if what I'm to do next is physically demanding or if I am to stand still and meddle with stuff and then take insulin and eat accordingly. Then suddenly something acute comes along, and one has to speed up and work hard, and then you get low blood sugar and then you need to sit down and get it under control and then get started again. Yeah, it [diabetes] takes up a lot of room and it requires good planning both when it comes to work or if you just want to go for a run. (Kurt, forties, T1D 38 months)

The daily hassle of having to engage in self-management behaviours was echoed by most participants. When speaking about self-management they pinpointed that there were various levels and aspects they had to relate to. Adapting their new technical skills into their day-to-day activities; the adjustments they had to make in their food choices

and things they were no longer able to do. They identified that recognising that having to live with these requirements and limitations was quite challenging. One participant contrasted her acceptance that diabetes is enduring with the fact that it is also all-encompassing:

I've come to terms in the fact that I can't get rid of it. That's it. I've got it. I've nearly come to terms with things I have to do and things I mustn't do and things I can't do. So, I'm getting there, but... [it's] a very slow process. (Judy, fifties, T1D 5 months)

Therefore, the emotional response to the perception of loss that follows the diagnosis seems on one level to be part of the adaptive process as it drives reflective thinking as they move toward some form of acceptance of diabetes in their lives. However, on another level it generates ongoing negative emotions that can lead to compromising adaptive behaviours and a sense of distress.

Acceptance of diabetes

Participants identified that acceptance of diabetes took quite some time. In this sense, acceptance was described as part of the ongoing process of adapting to their life with diabetes. In their narratives various aspects of acceptance and their influence on the adaptive process were described. For most participants a measure of their level of acceptance was expressed in relation to how engaged in their self-management they were, although they also thought that this was only one aspect of acceptance. As one participant explained acceptance occurs on different levels:

Well, the reality of it hasn't quite come to me yet. Eh... so acceptance, well I've accepted it to the extent where I'm doing it [self-management] every day but... but... the fact that it's going to stay with me every day for the rest of my life, that probably hasn't quite dawned on me yet. (Stina, twenties, T1D 16 months)

The extent of their acceptance, to some degree, reflected their commitment to self-management behaviour activities, although there was some disassociation between these behaviours and developing a sense of responsibility for controlling their diabetes, as indicated by Amy (twenties, T1D 38 months):

So I might still be in denial. I think I've accepted I'll have this for the rest of my life but it's accepting that I have to control it. Is not there yet [laughs] (...) My HbA1c is as high as, nearly, no, it was twelve when I was diagnosed and then it came down to nine three months later. It's back up at nine. So I'm a bit cross [chuckles]). So I want to get that down. Every time I try and get it down and (p) I say it never does, I never get it down and so maybe I'm not at acceptance yet.

The meaning of accepting diabetes was contested by some. They felt that accepting diabetes would be an indication that they were overcome by the disease and had passively given in to its demands. In their view, acceptance was more about recognising their new life situation and taking control over it by fully engaging in behaviours that would allow them to maintain their wellbeing. In making the decision to control their diabetes, they accepted having to take diabetes self-management behaviours into account and make the necessary changes. As one participant put it:

You have to accept that it is never going to go away. And it... maybe you have to accept that it's something that you are always going to have to manage, rather than accepting... see, for me, when I say... when you say or when anybody says 'Accept it', it makes me feel that it's something that I have to just live with and I have no control over, or there's... nothing I can do about it. But if you say 'Accept it', or 'Accept that you have to manage it', for me, I think that has more positive connotations, and in that way, yes, I do think that you have to accept that you have to manage this disease... but that might mean different things to different people, and for me that means testing frequently, eating the right foods, exercise, diet; all that kind of stuff, and that is part of good management. (John, thirties, T1D 31 months)

Another feature of acceptance was highlighted by some participants. They suggested that although acceptance is a proactive choice, lacking acceptance could potentially be harmful to them and hamper adaptation to their new life situation. While they were fully aware of the danger if they chose to ignore the basic management requirements, it was still demanding to fully accept everything about diabetes:

Well, by and large I'm accepting of it. And, you know, if I don't comply, well, then things will go wrong. (Lene, sixties, T1D 34 months)

The view that acceptance was a process within their adaptation emphasised the temporal aspect of acceptance. Participants largely described acceptance as a multifaceted and lengthy process that continued to confront them, especially when new situations were encountered. Commenting on this, one participant said:

I think time is important. It's not like a flick of a switch, it's a process (...) in terms of diabetes I mean I've been diabetic for four years. This is probably the most accepting I've been of it. Sometimes it's difficult, but you know, a lot of people have difficulty and life is, it can't be manually timed, it has to be probably for most people a very long process. That just comes from experience I mean you just, because there are days when something new happens with diabetes, you're not ready for it and I was experiencing that over time and I found that I just have to deal with every situation. (Bill, twenties, T1D 46 months)

While most participants agreed that the passing of time, including their experiential learning, was conducive for adapting to diabetes, this was not always the case. In one case, the participant related his resentment and anger towards diabetes, and during the first interview explicitly expressed his disinclination to accept diabetes:

But then again, I'm never going to accept diabetes. I'm going to be one of those people that just will not. (Jack, thirties, T1D 4 months)

During the time passing between the interviews he had been struggling with adapting to diabetes. At the second interview he repeated his reluctance to accept diabetes albeit keeping a slight option open that acceptance might happen at some point:

I mean, just at the moment for me it's just very difficult to actually just, you know, I guess I still haven't accepted it and, as I said, I probably never will. (Jack, thirties, T1D 4 months).

Therefore, participants experienced emotional challenges immediately following their diagnosis and in the ensuing process of adapting to life with diabetes. In their narratives, participants expressed their feelings and thoughts in relation to the consequences diabetes had imposed on their lives. While their feelings of grief and loss of their prior life were seen across the narratives, there were differences in the ways in which participants managed these feelings. The data suggest that the personal realisation of diabetes as an enduring and all-encompassing disease was a common feature in the process of acceptance of the disease, the level of this realisation may shape adaptation to diabetes.

A changed life situation

While participants largely felt that it was important for them to try and continue with most aspects of their lives before their diabetes, they experienced significant limitations and some stress in trying to sustain their usual activities. The way they perceived and made sense of these limitations influenced their view on diabetes and how they adapted to life with diabetes. Within the individual narratives, the limitations and ensuing life changes imposed by diabetes were expressed in a variety of ways. While relating his experiences, Bill (twenties, T1D 46 months) asserted that there was an imbalance between the optimal scenario involving no limitations and actual scenarios where some restrictions had to be observed, again with some emotional consequences:

Bill: You as a diabetic can do whatever [you] want, within reason. [You] can't go eat thousands of pounds of sugar, but you can do anything. It shouldn't be able to stop you doing what you want to do... [sighs]

Interviewer: But does it... do you think it does stop people from doing something?

Bill: Certain things. Certain things. I can't drink as much as I used to, but I don't want to do that anymore (...) It does stop you doing certain things. You have to be sensible with it. And you can, as a diabetic, go out and eat a whole chocolate cake, but you shouldn't. You do have to be fairly responsible with it. You have to kind of understand that there are certain limitations. You can enjoy yourself. You can... As long as you're... as long as you have the understanding of the condition (...) It's... it shouldn't... if you have a good understanding of your condition, and the complications that come with it, it shouldn't stop you doing 99.9% of the things in this world. I've found that it hasn't ever stopped me doing anything that I want to do. Not that I can think of. I've run a half marathon. It didn't affect me, because I knew what I should... I knew what I had to do. It doesn't affect me with my day to day life all that much. I can't drink 'cause alcohol's poison to diabetics sometimes, but that's fine. Sometimes you do feel like you're missing out, but...

Interviewer: Missing out?

Bill: Say if all my friends go out and get absolutely hammered. Like, drink a huge amount. I can't do that, but I save £50, so... [laughs] I don't feel awful the next day, and I get a lot of stories to tell, which is great. But you have to kind of... you have to have that mind-set. OK, it just is what it is. Sometimes it's really difficult, sometimes it's really frustrating.

Another way of dealing with and trying to overcome limitations was to contest and challenge them. For a few participants that included experimenting with activities they had not done before to prove to themselves that diabetes was not stopping them. For example, when comparing himself to other people with chronic conditions who would stop doing certain things, one participant said:

I'd rather prove that I can do so much more. The things I wasn't able to do before I strive the more to do because I've got diabetes. (Mark, thirties, T1D 28 months)

However, Mark also acknowledged that challenging the inherent limitations of diabetes could be complex and was not always possible. His day-to-day life influenced

his perception of the limitations and his ability to overcome them. He, too, spoke about the ambiguity and the emotional work involved in keeping up the notion of being able to do everything despite having diabetes:

The limitations seem bigger on a bad day. So on the other days, when you convince yourself that you can do all the things that you want to, and then you have this kind of day when it totally dawns upon you that you can't. Then everything becomes like a load of shit, you know.

In all cases, the participants reported that their changed life context involved having to plan ahead and anticipate how they might have to accommodate diabetes in their activities. In contrast to their former flexibility when engaging in various activities, they now constantly had to be prepared to take preventive measures such as carrying their devices and fast acting carbohydrates with them to avoid having hypoglycaemia or to be able to take additional insulin if needed. Participants had a heightened awareness of their need for insulin and the potentially deadly consequences to them should they not be able to access it. They were also aware of the hazard of insulin and its potential to harm them if they miscalculated their dose. Such an underlying potential threat instilled some anxiety in their behaviours and their dependence on the devices necessary to enable them to manage their diabetes. The need to have constant access to their diabetes equipment was also viewed as coercive and as an outward sign of their changed life situation and the restrictions it had placed upon their lives:

I'm having to think and plan more. For example, carrying that stupid needle around with me. Having to carry things around with me. It really annoys me. It shouldn't do because obviously I have to have it (...) with me, and it's the 'have to' I don't like. It's like I'm going against... authority. I know it's silly. (Judy, fifties, T1D 5 months)

Diabetes was constantly in the back of their minds, having always to be alert and ready to act on changes in bodily signals owing to high or low blood glucose levels. A further distinction was the interruptions that diabetes self-management activities made to

their daily rhythm. These interruptions again required applying their newly learned skills so that the intrusion would be minimal. Sometimes they could plan their self-management behaviours to fit their schedule such as measuring their blood glucose and injecting their insulin before a meal. However, at other times such as when encountering hypoglycaemia or feeling tired because of a high blood glucose, the interruptions were unplanned and unwelcome. Adapting to such situations meant that they would need to carry their diabetes devices and having fast acting carbohydrates available and thereby they were able to reduce potential negative consequences of these interruptions. Having to do this was unlike what “normal” people without diabetes have to do. Because of this, participants felt distinct from others and some struggled with having to carry something all the time. Talking about these issues a participant said:

Lisa: Like some days it's really good and I don't really think that much about it and then other days I do and that can be even positively or negatively and it does sometimes feed into like the anxiety and also the feeling different from the norm and really conscious. For example, if I start a new placement I'm like 'OK, we've got like the standard stuff like notes and like names and know where I'm going,' and I'm like 'Have I got my diabetes kit, have I got my glucose tablets just in case and have I got snacks and what food am I taking?' and it's kind of like it rolls on from there. It has impacted I guess just to go back to the question about how it's impacted change in my life, I think it makes it harder to get out the door so quickly, it makes my morning routine longer to have to test when I get up. It's almost like the first thing I do now, test, inject and then like wait a little while, have breakfast, have I taken the right insulin, like deal with if I haven't or feeling high or as the stuff goes through me and then going on with my day and remembering to check it again if I'm busy and then checking again for lunch and de, de, de. I think it makes you fragment your day more if that makes sense?

Interviewer: Mm, that makes sense.

Lisa: So it's not just broken up by work, it's broken up by diabetes o'clock kind of thing. (Lisa, twenties, T1D 35 months)

Therefore, participants identified the limitations that diabetes brought on their lives as a major change in their life situation. They spoke about how they needed to learn to adapt their lives to these changes and through experiential learning develop strategies to minimise the impact of diabetes on their day-to-day routines and activities.

Identity

The participants' different illness experiences and the varying course of the disease influenced how they re-constructed their view of themselves, with that view varying depending on their experiences. The label they used to frame their diabetes illustrated this view. While participants were ambivalent in relation to whether diabetes was to be perceived as a disease or a condition, most participants did not perceive themselves as being ill. In their view labelling diabetes as a disease indicated frailty. However, this view varied depending on how they were feeling about their diabetes, as expressed by Mark (thirties, T1D 28 months):

Mark: I'm at my best if I can have my numbers between 5 and 7 throughout the day, and they really shouldn't fluctuate more than between 5 and 7. And most days when I'm active I can actually keep them there because then I know that if I eat this, take that insulin, then it adds up if I eat that in two hours because there's still some insulin left in the body. And it would be even easier if I could be a little more ahead of things. But then again that's my need to be in control.

Interviewer: And the days where it can't be done and you get annoyed as you mentioned, are you annoyed with yourself or with diabetes?

Mark: I guess it's mainly with diabetes. I think it's a shitty disease. Do they call it a disease, or what do they call it?

Interviewer: What do you call it?

Mark: Normally I actually don't call it a disease.

Interviewer: No?

Mark: It's because disease is a weak thing.

Interviewer: What do you call it then?

Mark: Normally I just call it diabetes (...) But on the bad days, it's a disease. On those days it's a nuisance. It's something that's blocking the way.

The way participants re-constructed their view of themselves in the context of their health was also referenced with the potential for the impact of the disease to change, particularly if they were to develop complications. They identified that diabetes is more of a disease if you have complications, which generated anxiety. This anxiety about complications was a core part of their identification of the meaning of a life with diabetes, with the feeling that if they do not manage it well there will be '*a price to pay*' (Hans and Pia) later on.

Another feature of adapting to their life with diabetes was whether or not participants perceived diabetes as part of themselves or part of their lives. In their accounts most participants described how diabetes gradually became part of their identity as they understood more about the condition and how they could accommodate diabetes in their lives. Again, this process took time and was more or less constantly ongoing as participants negotiated their new life situation. Nick (twenties, T1D 17 months) related his experiences of finding a sustainable approach to living his life and accommodating his diabetes:

It's... I just didn't want it to sort of feel like an illness that had to be, like, tolerated and was just going to be a burden on everyday life. I just wanted to make it part of my life, because it is a part of my life, and I can't just treat it as if it's not, so that's what I meant by acceptance. It's just accepting it's there and living with it and making it part of me, who I am and what I need to do to get on.

When reflecting upon the proximity between diabetes and themselves, participants expressed various views. While some felt that diabetes was a part of their identity, they considered it as a distinct feature in their lives that could be compared to other features or characteristics. While they acknowledged that diabetes had an impact on their lives,

in their view it was important to stress that it was not their only feature, and it did not define them as a person. For example, one participant said:

Yes, so basically I guess it's, I've got diabetes, I know that. It's part of me but I see me as a whole thing. That's just a speck over here. There's lots to me, who I am, what I like to do, how I treat other people, how I go about what I am and then how I go about my life and in part that is what I do, what I want to do, what I want to achieve. Diabetes influence with that in a small manner, try to make it a small manner, how it influences my life. I don't want it to be a bigger influence on my life but it's something I have to take into consideration. (Adam, twenties, T1D 19 months)

In contrast, a few participants did not want to associate diabetes with their personal self at all. They felt coerced by diabetes and perceived it as external to them. While acknowledging that they had diabetes, they did not want to make it part of their identity. Instead they focused on managing the diabetes, trying to reduce its impact on their sense of self. Contrasting his view with those who felt diabetes was part of their identity, John (thirties, T1D 31 months) shared his reflections:

I guess that I would say that I only want things to be part of me if they're things that I have chosen to take on and made positive things. Otherwise, they're not there by choice and they're not beneficial to me, and therefore I do not want them to be part of me. So I'm making a choice that it's not part of me (...) For me, it's a negative thing. It's not part of me, and if... I think of it as a constant battle... a fight against it. So I definitely see it as something outside of me.

This quote also illustrated that while participants did not feel their diabetes was part of themselves, they spend much time trying to control it. In this sense the space they assigned for their diabetes became something of a battlefield in which they were actively trying to contest the amount of influence they would allow it to have on their lives.

Contrasting this view, other participants perceived themselves and diabetes as a single entity. In their view diabetes formed part of their identity and was integrated in

everything they did in life. When reflecting on the amount of space diabetes took up in their lives, one participant commented:

In principle, because it's me, diabetes takes up all the space. Because without diabetes I'm not me. It has become such a large part of my day-to-day life; I'm Jonas and I have diabetes but without it taking up space. So in one sense it doesn't take up any space at all but in another sense it takes up all the space because it's me. (Jonas, twenties, T1D 24 months)

The two faces of diabetes

There was a sense among some participants that the space diabetes took up in their lives could sometimes be positive and at other times negative. The negative sides were mainly connected to feeling inadequate and despondent towards the demands of diabetes. All participants reported having these kinds of emotions at times, some more often than others. The positive side of diabetes related to their sense of accomplishment when overcoming some of the challenges of living with diabetes. While the ways in which participants constructed meaning in relation to their diabetes varied, there were some distinctive features in this process among those who were younger and the older participants. The younger participants, while acknowledging the challenging aspects of their life with diabetes, also reported some positive elements in the way diabetes influenced their thinking and behaviour in pursuit of their future health and well-being. While the increased attention on their choice of foods was time-consuming and at times stressful, they recognised the benefit of eating healthier. Likewise, some participants reported that having diabetes was a motivating factor for doing more regular exercise. Several of the younger participants felt that living with and managing diabetes had in some ways increased their self-confidence. Overall this was reflected in a change in their general outlook on life with an emphasis on treasuring their personal health more than they did before they developed diabetes. They were also more conscious of being mindful of their values in life and their goals for the future. One participant contrasted his life before and after the diagnosis in this way:

Before I was diagnosed (...) I really didn't have that much of a life. I ate OK. My confidence was very poor. I had very low self-esteem... I looked after myself OK, but... looking back, not really. I drank a lot, spent too much money (...) And now I look at myself. I'm far fitter. I feel far healthier (...) My self-esteem is far better. I have much better confidence. (Bill, twenties, T1D 46 months)

Such views, however, were contested by the older participants. Although some could appreciate the benefit of healthier eating, they failed to see other positive elements and felt that their lives were disrupted by diabetes at a time where they had managed to build a life that they were content with.

The thing is it's... it's happened right at a point of my life where I've actually just got comfortable with myself and now I have to change everything again. (Jack, thirties, T1D 4 months)

Therefore, in their view, the positive aspects of diabetes identified by the younger participants were counterpoised with the major disruption that diabetes brought to their habitus. Hence diabetes created an internal conflict with their desire to relate to their diabetes as a focus for their future health against its imposition on their day-to-day life choices and future life plans. While this conflict could lead to frustration, it also expressed itself as an energy for adaptation as they could view the efforts placed on self-management in the context of health rewards in the future and their general sense of well-being. The way this style of thinking could be helpful to them in their early exposure to diabetes was reflected in this comment from Andy (twenties, T1D 15 months):

And it tests your resolve, it comes out of nowhere, shit happens and you're like forced, you have no alternative, you're absolutely forced to confront it and make changes and deal with it and once you've got on top of it and got it working in your life there's an amount of pride there, you feel like you've achieved something and not let it better you. So I try and emphasise those elements to myself obviously.

In essence, their perception of diabetes was that it mandated them to consider their health behaviours explicitly in their daily lives. While this perception may suggest a positive approach to self-management, it could come at a cost as it emphasised their personal responsibility and a sense of personal failure if things did not go according to plan.

Meeting the diabetes expectations

An aspect that seemed to influence the participants' identification of diabetes in relation to themselves, was how successful they felt they were in managing their diabetes. This was often expressed in relation to the difficulties they experienced in trying to achieve the blood glucose targets, as they often found that their glucose levels fluctuated and were unpredictable. Participants felt that variations in blood glucose levels were a reflection of their ability to control their diabetes. High values were particularly regarded to be a sign of their failure to live up to their own and their health care professional's expectations of being able to stay within a narrow blood glucose range. Some participants were extremely hard on themselves when seeing values that were above their targets and expressed disappointment in not being able to manage their diabetes the way they would like to. There was a sense of catastrophe in some who connected having a high value to their future risk of complications. Often participants were not informed about the multitude of factors that could potentially influence their blood glucose values. They did not understand why their blood glucose values fluctuated and therefore they attributed the cause of having high glucose levels to their own lack of ability to manage their diabetes. The pressure they put on themselves regarding always meeting their targets were quite heavy and burdensome as illustrated by Alice (sixties, T1D 33 months):

*Alice: I keep trying to do things better all the time. I'm **trying** to do better and...*

Interviewer: What does it mean for you to do better?

Alice: Well, then my blood glucose has to be between around four or five and ten. Four and ten. Ideally five and eight. And preferably I should... be feeling

good, you know... I get annoyed with myself when I make mistakes which you sometimes do; like if one forgets something.

Interviewer: And what kind of mistakes would annoy you?

Alice: Well, like yesterday when taking the basal, the insulin was leaking when I removed the needle. And then one is left with the thought 'How much insulin did I get?' (...) And then I have to live with that for the following 24 hours and then find out how to manage that. Things like that annoy me.

Over time some participants came to understand that they were not able to be in complete control all the time. Through various experiences with controlling diabetes they eventually learned to adapt their expectation of themselves to a more realistic level. Consequently, they were able to relieve some of the pressure while still striving to reach their targets. They learned to live with the occasional high blood glucose level without having to beat themselves up over it. When reflecting on this issue one participant said:

Mie: The longer time passes I think I just accept it and take it nice and easy (...) I've probably changed my attitude a bit and I think it's because of the time passing.

Interviewer: You mentioned that you had accepted it?

Mie: Yes, well, I don't know... I don't know if I've fully accepted it yet but... I can feel that it gets better and better (...) Maybe it has a lot to do with high blood glucose values or... about not being so hard on oneself... that eh... that helps me a lot. (Mie, twenties, T1D 19 months)

Other participants, who also initially aimed for a narrow blood glucose target, expressed how difficult it was for them to achieve their goals. They felt like a whip was cracking over them and they were stressed by the constant demands of diabetes. They explained that while in their early experience of the disease they worked hard on trying to manage their glucose level, as time passed they became more easy-going in relation to what they considered an acceptable range of their blood glucose values. They felt that trying to attain the perfect values was such arduous labour that it took away their

spirits and engulfed their lives. Therefore, they decided to privilege their life over the illness for a period of time. However, in some participants, their fear of getting complications later in life was constantly underpinning their decision and produced feelings of apprehension and not making ends meet. For example, one participant said:

I've had diabetes for a while now so I'm more easy-going about it and maybe I'm thinking 'Well, it's not happening until later on' but I am fully aware that if I don't have it under control then something will happen... (Hans, forties, T1D 28 months)

While most participants actively worked to enhance their self-management skills to become successful in meeting the diabetes expectations, a few participants defied doing this as they found it was interfering too much with their previous lifestyle. Instead they concentrated their efforts to successfully minimise the role diabetes played in their lives. They resisted making certain changes and were reluctant to engage in some self-management behaviours. This was evident in their choice of foods, such as regularly eating excessive amounts of high sugary foods; and by limiting the number of blood glucose measurements to decrease the perceived burden of diabetes. For example, one participant said:

I will still eat bags of sweets because, quite frankly, you know, I didn't grow up as a baby diabetic, I didn't have this all my life, I've had this literally in the middle of my life, there's no way I'm going to bloody change. (Jack, thirties, T1D 4 months)

This group of participants were aware of the potential risks of getting complications if their blood glucose values were high consistently, but they perceived the risks as impalpable and so distant from their present life that they did not place much focus on them. In consequence, they tended to be less engaged in developing their self-management behaviours and had made minimal changes to their lifestyle. Despite their effort to minimise their engagement with diabetes and disavow potential consequences they were cognisant at some level that their approach was not beneficial

long term. They spoke about having ambivalent feelings when reflecting on the potential consequences of their approach to self-management:

I wish diabetes would take up more room and that I would be more conscious of the consequences of my actions instead of disowning them. It's not good in the long run; there's also a day tomorrow. (Tom, twenties, T1D 32 months)

Therefore, the expectations placed on achieving 'good' diabetes control by themselves and by health care professionals can make participants feel bad and identify as an unable person when they do not meet these ideals. This can also compound a sense of failure and drive negative emotional adaptations and thinking patterns.

Social relationships

An additional feature of how participants had to adapt their lives was their construction of a social identity as a person with diabetes as they interacted with other people in the context of scenes from their everyday life, their work/study life and their engagement in the wider society. Participants had to learn how to integrate diabetes in their social world. The way the participants integrated diabetes in their social habitus was influenced by their perception of others' opinion of them and their own perception of diabetes and themselves. These perceptions to some degree affected how they interacted with others and guided their choices regarding ways of communicating about diabetes. Participants were conscious about what they shared about their life with diabetes to whom and in what context.

Renegotiating relationships

During their process of adapting to life with diabetes, participants recognised that it affected their relationships in various ways. At the time of diagnosis participants involved their closest family as early as possible and for most their family and/or close relations provided immediate support. In their accounts participants often reported that their families reacted with sadness and concern while at the same time trying to

encourage them. For the younger participants it was often their parents who were involved and for the older participants or those in a relationship it was their partner and in some cases their adult children. Having diabetes was a completely new experience for both the person who was diagnosed and their family members. Therefore, it was difficult for some to articulate how they felt about the diagnosis and the prospect of living with a chronic illness. However, participants reported that they tried to voice their feelings about the diagnosis to their significant others and in most cases, they shared concerns and difficult emotions with each other.

For those in intimate relationships and those with children, some of their everyday routines had to be changed in order to accommodate their diabetes, which could be quite restrictive as illustrated in the comment below:

Well, my day is organised so that I have time to take my insulin before having something to eat and then getting the kids ready. Not many things have to go wrong before things are a mess. I'm fairly dependent on taking insulin at about the same time or my blood glucose values either go up or down. So that can be very frustrating. And then you feel stuck. That you can't just do what you want.
(Mark, thirties, 28 months).

A common way for their families to show support was by changing their food in accordance with the participants' needs. This required learning more about carbohydrates and changing their shopping routines. Participants found it helpful when they were able to bring their partners to consultations at the diabetes clinic to share the learning. Making these adjustments and learning how to take diabetes into account when preparing a meal was a process for both the participants and their partners. Their partners' level of involvement and influence on their choice of food could sometimes be conflicting with participants' immediate wishes. Potential confrontations were very much dependent on their mutual communication skills, how worried partners were and how participants perceived the meddling. This was illustrated in Tom's story in which his girlfriend made a comment about refraining from buying candy when they were out shopping:

Well, the moment she says it it's annoying. But... when I think about it it's only positive because... she only wants the best for me and she can support me in the choices I make. When I'm in Sainsbury and just want to buy some candy and put it in the basket, I don't appreciate her saying: 'I think that's a bad idea,' when I've had a bad day and just want something (...) however, she does it in a very very good way. She is not by any means pushy and she doesn't say it to annoy me. She is also understanding if I don't want to oblige her. She knows me very well. (Tom, twenties, T1D 32 months)

Another change for partners and children following the diabetes diagnosis was their awareness of the participants' well-being and the potential risk of experiencing episodes of hypoglycaemia. Participants described that their partners or children 'kept an eye on' them and were ready to assist them in case such episodes happened, which gave them a sense of security. While participants appreciated the concern and support in self-management their partners provided, they did not always explore their partners' thoughts and feelings in relation to their condition. When asked why his girlfriend reminded him to take his medication, Emil reflected:

I don't know [why she reminded me]. She asks all sorts of questions. Actually, I haven't thought about that. She might be worried, maybe? (Emil, twenties, T1D 3 months)

In this sense their partners' adaptive process was somewhat silenced and the optimal supportive benefit for their mutual adaptation was not necessarily fulfilled.

Participants were also guarded about being too dependent on the support from their family and friends as it could erode the quality of their relationship. These feelings related to situations where others had to take special precautions on their behalf such as cooking dinner without using too much sugar. Initially some felt that they could or would not ask for special treatment when dining outside their home because they prioritised fitting in and not troubling others more than attending to their own needs. But in time they would be more aware of the consequences of not attending to their

own needs and felt more comfortable about expressing these. Commenting on this change in attitude, one participant said:

You know when someone else is going to cook for me instead of simply eating what they're going to make, when you go and visit someone or you go to a party or whatever I now try and assert slightly more strongly what I need them to provide me with, rather than simply having what they've got. Because... you know I was basically being polite and I didn't want to upset anyone and be a demanding guest (...) And I kind of, you know you've got to weigh up whether or not it's worth it to you to eat something crap that's going to make you feel bad against them having to think about it. (Andy, twenties, T1D 15 months)

Interactions with peers

While there was a general sense among the participants of support and understanding from their family and friends, there was an awareness of being different from them and that they now had a changed and unique life situation. Therefore, despite the support provided to them by their peers, some participants expressed feeling distant from others, as people without diabetes did not fully understand what living with diabetes entailed. When contrasting his friends' struggles in life with his own struggle to manage diabetes, one participant said:

Jonas: It annoys me if people complain about other things because they don't know what it's like to have troubles, I don't think.

Interviewer: What kind of things would they complain about?

*Jonas: Well, it could be worries about trifles. I can't think of something on the top of my head. It could be anything. Trifles that I take care of without thinking. It's because I feel they should take into consideration that they have a life where everything runs smoothly (...) If they complain when going to the gym [they should consider] that I'm working and going to the gym **and** running my diabetes on top of that. (Jonas, twenties, T1D 24 months)*

There was a consciousness among participants that the specific understanding of what life with diabetes entailed could not be found in people who did not live with the condition themselves. This was reflective of broadly positive views regarding peer support from others with diabetes. This view was consistent in both those who had experienced some interaction with others with diabetes and those who had not, as illustrated in this comment:

I think sort of another group of fellow diabetics... young, old, male, female. Not children; adults. Children are different. But all sorts of different adults. That, I would like. You know like you have AA meetings? Something like that. Because then they can actually advise you and also squash any concerns you may or may not have. (Judy, fifties, T1D 5 months)

Participants who had experienced some form of peer support explicitly referred to the value of meeting others who were able to completely understand what living with diabetes was all about. Some participants had met others with diabetes by coincidence and were given the opportunity to share some of their thoughts and worries. One example of that was one participant who shared a room with an older man when he was admitted to the hospital at diagnosis:

So I asked him about things I was thinking about such as could I still have a beer and have a night out. Honestly, I thought that maybe I wouldn't be able to do that. I talked to him about that and he said that of course I could do that and that I could live a completely normal life. He had lived with it for 40-50 years, so it was really good to talk to him actually. (Dan, twenties, T1D 31 months)

Other participants had taken part in various group sessions and all had greatly benefitted from sharing experiences. In some cases, the people the participants met had been living with diabetes for a very long time, and meeting someone like that instilled hope in them regarding their future life with diabetes. When relating her experience of meeting a range of others with diabetes at a structured education course, one participant said:

But on the DAFNE I met people. There was another girl who had it probably just about the same amount of time as me and there were another two guys they'd had it about three to four years. There were two gentlemen, one gentleman had it 48 years and there was lots he didn't know, which was surprising. But to hear the point of view from the people that attended the course who have had it most of their lives because they were in their late 40s and early 50s. To see how they've managed it and that they're OK and they didn't even have the knowledge we've got now. It kind of took the edge off my anxiety (...) because they seemed, not perfect, no one in there was managing a lot better particularly, but everyone was OK. (Sue, twenties, T1D 4 months)

While the participants on the whole agreed that peer support should be available for adults newly diagnosed with type 1 diabetes, a few of those who did not have any experience of meeting others were reluctant to join group sessions with other people with diabetes. They did not want to identify themselves with diabetes and did not see any benefit to themselves by taking part in conversations that revolved around specific aspects of diabetes management. One participant, who only joined a group session on carbohydrate counting because it was mandatory for getting an insulin pump reflected on his disinclination to take part:

I think it is really important to offer [peer support] eh... but for me I think I'm mostly... I haven't, I don't identify myself as type 1, I identify myself as having type 1. I think there's a difference (...) you know, I almost cannot bear the thought of having to listen to what food other people eat and things like that. (Emil, twenties, T1D 3 months)

Online communities provided another form of peer support. These communities were less intrusive and could be used anonymously if participants so wished. While participants who used the online forums didn't necessarily meet face to face with other people with diabetes they expressed a sense of togetherness through reading posts on various platforms. Recognising themselves in other people's narratives was a way of normalising their own experiences of adapting to life with diabetes. They highly valued

knowing they were not alone in their process of learning, as illustrated in the comment below:

You are part of a community, you know that there are... someone who has experienced the same things and it's not abnormal. (Hans, forties, T1D 28 months)

Therefore, peer support for adults newly diagnosed with type 1 diabetes can take many different forms and seems to help most people at different time points in the adaptive process across the diabetes trajectory. Overall, the entrance of diabetes into their lives reshapes many aspects of the person's social world. This involves adaptations to their personal relationships and the development of supportive or compensatory systems to enable continued social functioning.

Diabetes and work life

Following the diagnosis participants were aware that diabetes might influence their work life and that they would have to make some adjustments to their work routines. The participants who were employed recognised they had to let their manager know that they had been diagnosed with diabetes. However, because of their own limited experience with diabetes they were uncertain in what way and to what extent diabetes would affect their work. In addition, this aspect was not routinely addressed by health care professionals and left participants unprepared for this type of conversation with their employer. When asked about specific needs she felt were not attended to at diagnosis one participant said:

I think there's... especially newly diagnosed as an adult, maybe around work. Things like no-one really tells you, and I think work also don't really know, how it's going to affect you at work, and then you don't... 'cause it doesn't... obviously, nine times out of ten... I mean, I think there may be some professions where you'd be affected, but it shouldn't affect your work, but then... also there are the hospital appointments, and... and it's kind of negotiating that a little bit. (Jane, twenties, T1D 5 months)

There were variations in how understanding their workplace and colleagues were when they revealed that they had developed diabetes. Some participants had experienced difficulties in their work situation after their diagnosis such as having to fight for sufficient time to perform self-management behaviours or attend to episodes of hypoglycaemia. Feelings of harassment were mentioned by some and the lack of support made adapting to diabetes more challenging for this group of people. Their struggles with work-related problems were not addressed at their clinical appointments. A few participants felt left alone with these challenges and suggested more help should be available in such situations. As one participant put it:

*There was **no** help to be found **anywhere** (...) I think they [the health care professionals] could do more to help people [with work-related problems].*
(Lene, sixties, T1D 34 months)

In contrast, other participants experienced a high level of support and understanding from colleagues both in relation to having time for self-management and having time off to attend clinical appointments. This kind of support was conducive for adapting to diabetes within their work life. However, in addition to the common concern about performing sufficiently at work, participants identified their constant worry about having a hypoglycaemia and the potential effect that might have on their work performance. For example, when reflecting on how diabetes had affected his work, one participant said:

If I'm at work and I need to give a presentation or something and I don't like public speaking I kind of feel like this conspires against me because I have to worry about that as well, I have to worry about 'Am I nervous or am I having a hypoglycaemia?' You know all these ridiculous, little things, but they can affect you. (Andy, twenties, T1D 15 months)

Being a person with diabetes when entering new settings

Participants all had experiences of becoming part of a new environment before they were diagnosed with diabetes. As their life with diabetes progressed they found that

doing so while having diabetes was somewhat different. There were new concerns they had to face and find ways of accommodating diabetes in these situations.

Participants who applied for a new job or changed their jobs were often careful how and when they spoke about diabetes as they were concerned about the potential reaction from others and the consequences this information might have for them. They considered whether or not revealing their diagnosis would decrease their possibilities of getting the job or if their new colleagues would view them differently when knowing they had diabetes. One participant who was working freelance was often faced with these concerns. After having experienced a serious hypoglycaemic episode at work he had decided to always inform his employer and colleagues about his diabetes. However, he found that intimidating and it affected his self-esteem negatively because of his perception of other people's reactions to that information:

I guess the hardest thing I find is just I guess constantly having to tell people when you're in professional circumstances when people have the right and should know about the illness. I find working on a freelance basis that happens a lot because I'm always changing jobs. So that's hard and I always, and this old thing about self-awareness and insecurity, every time it's mentioned I just feel like after that's said the opinion has changed and they stop treating you as just a fellow employee and they just realise that they are perhaps looking out for you a little bit more and it's almost just [like a] condescending tone I guess in a way? But I don't know. Yeah, I feel like definitely the hardest thing is telling, having to tell people and understanding that their opinion on your ability might change, even though it won't. (Nick, twenties, T1D 17 months)

Participants' concerns were also evident when they met new people or became part of a new environment. One example of this in the narratives was in stories with participants being reluctant to talk about diabetes on their first dates. They were concerned about their date's knowledge about diabetes and their potential prejudice against people with a chronic illness. Therefore, they were cautious about when to reveal their illness and how to do it in order not to put themselves in an unfavourable

position. For example, one participant described her reflections relating to other people's perception of her in the following way:

Stina: It may be that those I'm dating think, 'Oh, she's one of those, she's difficult, she has a chronic condition. If we grow old together she may lose her feet or get something', you know? I think a lot about that.

Interviewer: How does that influence the way you're dating... or does it influence it at all?

Stina: Well, I probably wrap it in cotton wool, you know, avoid talking about the chronicity and all the things that might happen when you get older and all of the things one is more exposed to. I avoid talking about it because it's not something that adds value or something that adds value to me [chuckles]. So yes, it gets... I water it down and say, 'Oh it's just insulin and that's just how it is, and then you live healthy', and talk about the positive stuff instead of pointing out the negative stuff, yeah... (Stina, thirties, T1D 16 months)

In settings where participants did not engage directly with others, some chose not to disclose their diabetes, either because they thought it was irrelevant or because they did not want people to know about their condition. In most cases they were able to control the amount of information they made known about their diabetes. However, some participants had experienced a severe hypoglycaemia in public leaving them without control of who would be involved in their diabetes. Reflecting on this dilemma, one participant shared his thoughts about when to involve others in his diabetes:

Diabetes is not part of it when I'm at the local gym. I have my little rucksack with supplies if I start to feel bad, but these are people I don't know and don't have a relationship with so I don't want them to know that about me. And I don't have a need to promote the fact that I have diabetes. The other day I went to Toys-R-Us with my oldest daughter and [while we were there] I felt really bad with my blood glucose as low as 1.8 or something like that. So she runs to get some candy and then we have to explain afterwards what was wrong (...) I haven't tried that before and in hindsight that was completely unacceptable, it's

almost like stealing (...) So initially diabetes wasn't part of the situation but suddenly it was. (Mark, thirties, 28 months)

Therefore, another feature of adapting to diabetes was the way participants carried diabetes with them when entering old and new social circles. In most cases the level of openness was in their control. However, if they had a severe hypoglycaemia in public they lost this control.

The different languages of diabetes

In their narratives participants highlighted that communicating about diabetes was not always straightforward, as the common language of diabetes in the context of their interactions with health care professionals was often in technical terms focussing on glycaemic control. Following their diagnosis participants had to acquaint themselves with the health care professionals' language of diabetes. This new language contained many new constructs and privileged the technical aspects of managing diabetes focussing on the numbers associated with diabetes, rather than the emotional aspects of diabetes that constructed their inner diabetes language. These different languages reflected the dissonant agenda of the patient and the professional, as expressed by Bill (twenties, T1D 46 months):

Like, it sucks, absolutely. I know... like, no specialist who's in the NHS is going to sit there and go, 'Yeah, diabetes sucks', because they're paid to try and give you help. But no one's giving them the actual, real 'Well, yeah, it's definitely difficult, but if you do this and this and this, it can be much easier, and it can be dealt with better. And sometimes you can have bad days. Everyone has bad days'.

The narratives suggest that at times they were also happy to default to the health care professionals' agenda and the language of numbers as in some ways it meant they could avoid confronting some of these internal thoughts. In essence it felt safer talking about their technical self-management skills rather than speaking about their emotions, as one participant said:

At that time I don't think I was ready to be open so I just blanked out those feelings and said, 'Hey, it's fine and let's just stick to these numbers' because that's what I'm ready to relate to (...) And then when you've lived with it for a while you could bring it up again; 'How do you really feel about it?' (Mie, twenties, T1D 19 months)

However, this failure to raise and talk the emotional language of diabetes, concentrating instead on the professional discourse, could quickly become habituated such that their emotional responses to the diagnosis and their new life with diabetes were not considered, as illustrated by Stina (thirties, T1D 16 months):

No one at the hospital ever asked me if I needed to talk about it [the difficulties of living with diabetes].

This experience was echoed by another participant who reflected on the emotional aspects of his life with diabetes that were shared during the interview:

Erm, it's interesting, no-one's talked to me in the way that you're talking to me now about the psychological element of it. (Bob, twenties, T1D 13 months)

The health care professionals' limited attention to the emotional responses following their diagnosis left the participants with the perception that this aspect of their process of adapting to life with diabetes was less of a priority. However, the participants identified that diabetes had added a psychological burden on their lives that they could not ignore and had to relate to for some time following their diagnosis:

The first year was much more difficult. Much [more] difficult to cope. Really, it was (...) I found it... it took its toll. (Ruth, sixties, T1D 27 months)

Participants identified that communicating about the psychosocial aspects necessitated a trusting relationship with the health care professionals in which the participants felt confident enough to share their vulnerability. If the health care professionals did not initiate discussions about emotional aspects it was more difficult for participants to share their concerns because they felt these issues were not a

priority nor something the health care professionals were interested in. Talking about her perception of her relationship with the health care professionals one participant said:

Kath: You don't feel with the people you see that you would want to show that kind of ... weakness to it.

Interviewer: Weakness?

Kath: Like if you're low about dealing with it or you're struggling with it mentally, I wouldn't.

Interviewer: And why do you think you wouldn't want to show them that?

Kath: Because you haven't got that kind of rapport with them (...) only this one lady (...) I'd talk to her about it but the other doctor I see I wouldn't, you know, she's very much 'Your figures are good' or 'You need to adjust this, you know, do this' and it's like 'Oh check your feet, we'll get you booked in for your eyes', all of this, so yeah (...) They don't ask, whenever I see anyone here, they don't ask 'How are you dealing with it mentally?', nobody does, so...

Interviewer: Would that be helpful?

Kath: Yeah, I think so because then at least even if you didn't want to, you're being asked the question and then if you felt that you did, you could talk about it then, but not to be asked at all, it's just literally checking how good you are at injecting. It's a bit cold. (Kath, thirties, T1D 24 months)

The number centrality in the health care professional's language of diabetes and their failure to address the participants' inner diabetes language led to a sense of being judgemental and to misinterpretations. Participants reported that when their HbA1c was in the target range the health care professional would often commend them and then assume that they were doing well generally. While the participants appreciated this encouragement, many did not feel like they were doing well despite having achieved what the health care professional wanted. Commenting on this issue, one participant said:

Just because someone's doing well physically and managing the condition doesn't necessarily mean it's not having a psychological impact and I guess where I'm coming from is in the care I've had so far – which has been fantastic don't get me wrong – I don't think anyone has ever said, 'And how is that, and how does that make you feel?' or, 'How are you feeling about your care?' more so than just maybe an off the hand remark: 'Oh you're doing really well so you must be fine with it.' (Bob, twenties, T1D 13 months)

While the participants identified the lack of psychosocial support in the health care system they were cognisant that there were variations in what they needed at different time points in their diabetes trajectory. Therefore, they emphasised the personal approach and the need to make the support available without putting an additional burden on people.

The public and the personal narrative

A common problem when engaging with other people was the general ignorance about diabetes and their presumptions about the different types of the condition. These presumptions were often reinforced in the popular media and within the social discourse on diabetes. The public narrative in relation to type 1 diabetes was dominated by the idea that it was a genetic disease of children that was managed with insulin. Type 2 diabetes, on the other hand, was perceived as a self-induced older people's disease caused by being overweight and lack of exercise. However, there was not a public narrative about adults who were diagnosed with type 1 diabetes. Therefore, the participants did not fit in any of the diabetes categories and were frequently asked if they had been overweight previously, as people took for granted that they had type 2 diabetes. Many participants felt that type 2 diabetes received much more attention in the media leaving their condition less of a priority. In order to justify some of their challenges with diabetes, some felt a need to distance themselves from people with type 2 diabetes and explain that their condition was not self-inflicted.

Participants described variations in other people's views about diabetes and their approach to talking about it. While most people did not have much factual knowledge about diabetes many were quick to share their presumptions with the participants without giving much thought to what impact their comments could have. Some people made comments about knowing someone with diabetes who went blind, others made abrasive remarks about their insulin treatment. In her narrative, one of the participants shared her experiences of discussing her diabetes with others:

Helen: And the things people say sometimes, if they see you injecting, or once this girl at uni said, 'Oh, if I had to inject myself every day, I'd kill myself.' And I was like, 'Why do you think that's a good thing to say?' (Laughs) Like... yeah, but sort of people's reaction sometimes...

Interviewer: How do you react when people say things like that?

Helen: Well, in that specific instance, I was kind of... I was just so taken aback that I kind of ignored it, but a lot of the time people just ask questions, and... I feel like it should be annoying, but I don't really mind it because so many people think things that aren't true about diabetes that I kind of want to tell them what the truth is. (Helen, twenties, T1D 32 months)

Other participants echoed that they did not mind explaining about their diabetes if people were genuinely open and interested in learning more about it. However, among those people who had some knowledge of diabetes, there was a belief that type 1 diabetes could easily be managed with insulin. Because of the lack of a public narrative describing their situation, some participants felt it was difficult to share their full personal story of living with diabetes. People's misconceptions about the constant nature of diabetes and its management made some participants hold back in expressing their personal struggles with diabetes and explaining what living with diabetes was like. When people disregarded the hard work diabetes demanded of the participants, most of them felt their personal narrative was belittled and they felt dismissed. For example, one participant said:

It bugs [me] when people say 'Oh you've got type 1, that's alright. It's manageable if you just control it. It's fine', like if you just control a raging stallion it's fine (...) 'It's fine you just need to control it like anything.' Yeah, yeah I can just control an army or something like that, no problem [ironic tone of voice].
(Bob, twenties, T1D 13 months)

Participants were aware that they themselves did not have much knowledge about diabetes before they were diagnosed. Therefore, they understood that their personal narrative about diabetes developed through their experience of living with the condition. While they recognised that people living without the condition had a limited understanding of what living with diabetes was all about, there was still a sense of loneliness.

Reconstructing a view of self

In summary, participants identified that due to the appearance of diabetes in their lives, their own role in many of their familiar scenes changed. Therefore, over time they had to reconstruct their personal identity to incorporate diabetes, which for many seemed to involve a degree of emotional and social disruption. Their process of learning to live with diabetes entailed transference of their knowledge about diabetes to skills they could employ in their day-to-day lives. In this process they gradually integrated diabetes in the various scenes of their lives, as diabetes became a significant character in these scenes. The diabetes also created new life scenes both in terms of the day-to-day experience of living with diabetes and in their interactions with the formal world of diabetes in their encounter with the health care system. Overall, their adaptive process was largely determined by the person themselves and their emotional and social responses to it, with limited external direction or structure. In consequence, many participants formed some unhealthy thought processes and behaviours related to diabetes in this early period of adaptation to a life with diabetes.

Chapter summary

The data suggest that the experience of being diagnosed with and adapting to diabetes is distinct to each individual. However, the data also indicate that there are some common phenomena that seem to shape the way in which people respond to their diagnosis and move on to accommodate diabetes in their lives. The data suggest that the underlying phenomena that may contribute to this adaptive process are: their prior life experiences; their experience of the physical elements of the disease; their emotional responses to the diagnosis; the way diabetes is introduced to them and their ongoing interactions with health care professionals; their understanding of diabetes; the expectations placed on them and those they place upon themselves in relation to their diabetes control and behaviours; their perception of the impact diabetes has on their lives; their interactions with others (family and friends and the wider public); their perception of how others view them; and the extent to which they accept diabetes as part of themselves. These underlying phenomena reflect the multidimensional processes of learning about diabetes and learning to live with diabetes.

The following chapter proposes a series of theoretical models that seek to illustrate key underlying mechanisms that influence these complex processes of adapting to a life with diabetes, derived from the phenomena observed in the narratives. The chapter also identifies areas for intervention that could potentially benefit adults newly diagnosed with type 1 diabetes.

Chapter 6 Theoretical models for supportive intervention

Following on from the diabetes story this chapter suggests a series of theoretical models expressing aspects and mechanisms underlying the process of adapting to life with diabetes to inform the development of enhanced interventions for the study population. The identified models have been derived from a synthesis of the study findings, together with the outputs of the meta-synthesis presented in Chapter 2. They have been constructed to identify key phenomena of the adaptive process that could be targeted by various sources i.e. healthcare professionals, significant others or patient organisations to extend the support offered to adults newly diagnosed with type 1 diabetes. The models reflect the temporal nature of adaptation across the participants' trajectory from the presentation of the disease in their lives. Consequently, the models have been organised to reflect this trajectory. The models are derived from the data and express the key elements within those data that may influence patient outcomes. Each model is represented figuratively with explanatory text. Following the description of each model the potential modifiable elements within the models are identified with proposed strategies for intervention. These specific strategies are suggestions that could potentially be targeted in an intervention. However, the value and relevance of these proposed strategies would need to be explored in more detail using participatory methods involving patients and health care professionals to co-design an intervention. It is important to highlight that the suggested strategies may or may not be validated in the co-design process and furthermore, alternative strategies may be suggested by the PPI groups involved in the intervention development. The models have been developed as part of the overall design of the study following the MRC Complex Evaluation Framework as previously outlined.

Model 1: Pre-diagnosis

This model identifies the factors that may shape the health-seeking behaviours of adults when they develop diabetes symptoms and their interactions with health care professionals in the pre-diagnostic phase. The underpinning construct in this model is that there is a lack of understanding in relation to the potential of developing type 1

diabetes in adulthood. This lack of understanding is expressed at the macro and the micro levels reflecting two dimensions of the public narrative of diabetes.

The macro level relates to the participants' view that the general public perception of type 1 diabetes is that it is a disease that occurs in childhood. This perception is reinforced by the fact that much of the information that is available on the internet and from other media often emphasises that type 1 diabetes is a children's disease. As these misconceptions are prevalent in the general public, adults who develop symptoms may not attribute them to type 1 diabetes, potentially delaying diagnosis. There is also a general assumption that diabetes developed in adulthood is largely type 2 diabetes. This assumption may have a legacy beyond the context of the diagnosis, as it sets-up later areas of conflict where participants can feel misunderstood, and in some cases feel that they are being judged for having developed diabetes.

The micro level relates to the responses of health care professionals to the presentation of initial diabetes symptoms, as again there may be a lack of consideration for adulthood onset type 1 diabetes as a potential diagnosis. The narratives revealed that when participants approached frontline care providers such as GPs or opticians with their symptoms, health care professionals were not always alert to type 1 diabetes. In some cases this delayed the instigation of appropriate therapy leading to DKA or to them being misclassified as having type 2 diabetes, both of which could present significant hazard and uncertainty for the person.

The model also suggests that these macro and micro level misconceptions may compound each other, creating confusion for the individual as they try to explain what is happening to them. Such experiences may be distressing and have a negative influence on their diagnostic experience. The narratives suggested that these early experiences may also have a more enduring impact on their relationships with health care professionals, potentially causing mistrust. At a deeper level they may also influence their psychological and social adaptation to the condition, by informing their emotional and behavioural responses and shaping how others respond to them. Hence it may be important to allow patients the opportunity to go over these experiences, so they can be acknowledged and attended to following diagnosis.

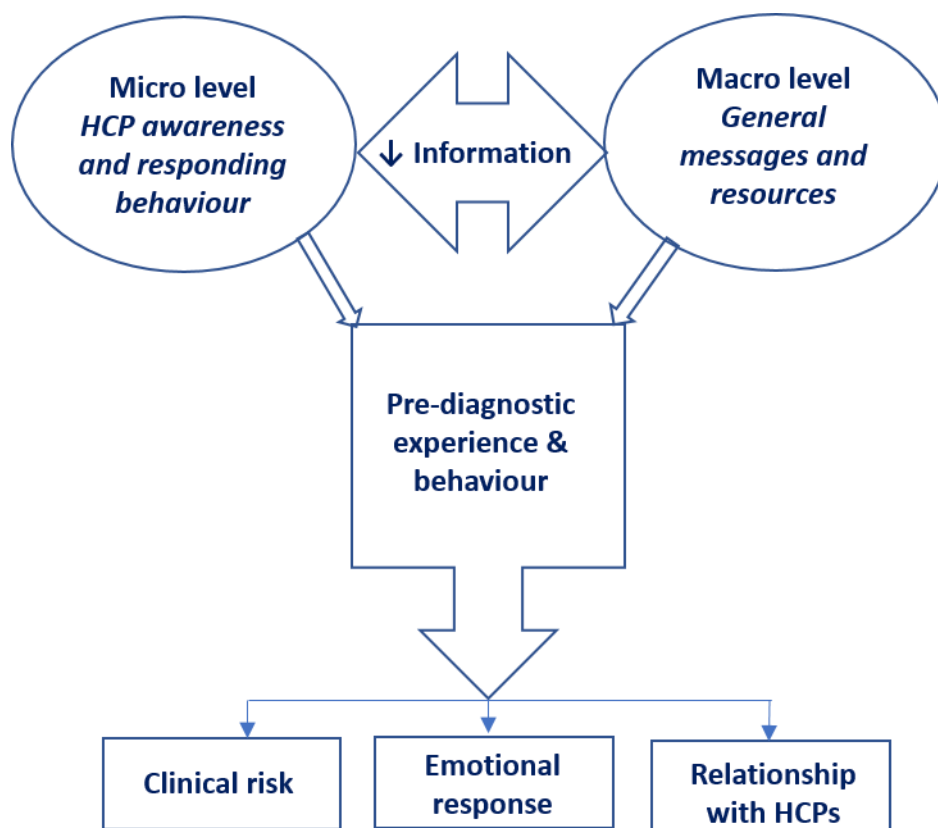


Figure 5 Prediagnosis

From this model potential modifiable areas for intervention were identified. Future approaches could include:

1. Increasing the awareness of frontline health care professionals of the potential of type 1 diabetes developing in adulthood, and their knowledge of appropriate care pathways.
2. Enhancing public information resources such as diabetes and health care websites so that they emphasise that type 1 diabetes may occur at any age and signpost the appropriate health-seeking behaviours.
3. Using wider media to promote general public awareness that type 1 diabetes extends beyond childhood and adolescents.
4. Providing a supportive opportunity for participants to reflect on and recount their pre-diagnostic experiences and attend to any emotional reactions that may have formulated a negative perception of diabetes during their experience (this intervention should occur soon after diagnosis).

Model 2: The diagnosis

This model characterises the factors that shape patients' experience of the diagnosis and the ensuing adaptive process. It also identifies the potential importance of their interactions with significant others, the health system and health professionals as they try to identify diabetes as a feature of their lives.

The shaping factors in this model are the patients' prior illness perceptions, their prior life experience and the severity of their symptoms. When diabetes symptoms occur, patients' responses are shaped by their past experiences of illness which are generally transient in nature. Their perception and experience of symptoms can be accompanied by anxiety for both patients and their significant others. The way these concerns are attended to by health care professionals may lead to negative emotional responses and impact their ongoing interactions with health professionals. The patients need reassurance that their symptoms can be ameliorated and information that is responsive to them individually. The narratives showed that patients often feel overloaded with information at this stage, and the information given may on the one hand be too reassuring or, on the other, place too much emphasis on complications. Both of these approaches can lead to future emotional difficulties, with patients feeling that false reassurances that they can live a 'normal' life are in conflict with their later experiences of the ongoing challenges they face with the disease. An emphasis on the potential hazards of diabetes may induce an enduring fear of these complications. In both of these scenarios the uniqueness of the person's own experience of diabetes is downplayed or neglected impacting their future adaptive process and influencing their bio-psycho-social adaptation to diabetes. Finally, it may be important to balance the technical and emotional support provided to patients. The narratives suggest that there is a strong emphasis on the technical aspects of insulin use in this phase, with less emphasis on patients' psychological reactions and social challenges.

Therefore, responding to patients in a way that attends to their individual concerns with realistic accounts of what they can expect may be more useful. It may also be beneficial to assess their emotional response and reaction to the information and clarify how the person has processed that information. In addition, the informational needs of significant others should be addressed and harmonised with that of the

patient. There may be a role for providing some self-help resources to help patients understand at their own pace the experience of living with diabetes. As with the pre-diagnostic model, reviewing their experiences of the diagnosis and attending to these initial and potentially formative emotional responses may be useful in promoting adaptive strategies. A further consideration may be early exposure to peers to help address the sense of isolation some patients experience to help normalise some of their experiences.

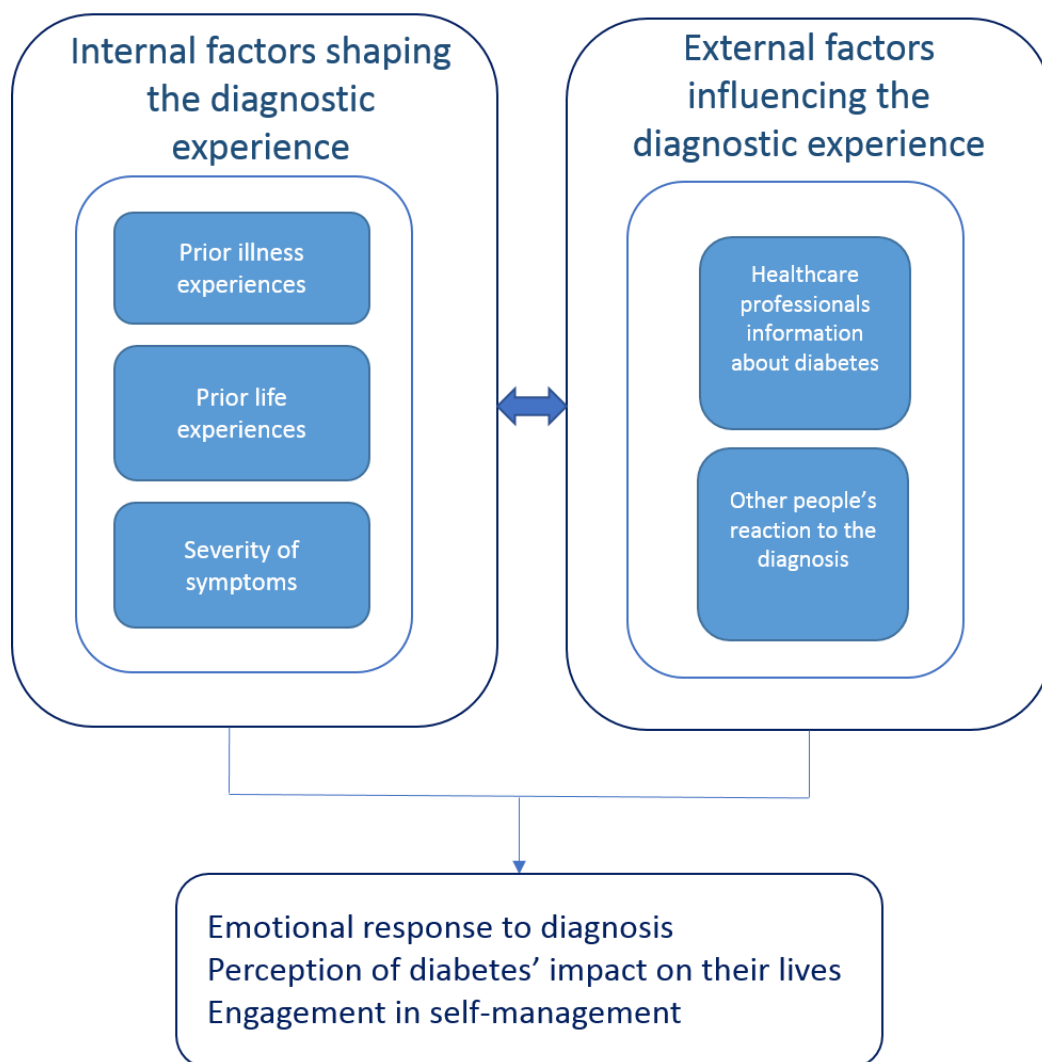


Figure 6 The diagnosis

From this model potential modifiable areas for intervention were identified. Future approaches could include:

1. Immediately reassuring patients that diabetes can be treated and managed.
2. Providing more realistic information that acknowledges the complexity of living with diabetes, aligned with positive strategies that emphasise how this complexity can be managed.
3. Attending to the emotional reactions that patients have formulated during their initial experience of diabetes (this links to model 1).
4. Identifying from the outset that accommodating diabetes into their lives will encompass both bio-medical and psychosocial adaptations signalling what resources will be available to help them with this.
5. Normalising emotional reactions by giving them access to common responses to the diagnosis of diabetes in adulthood and potential early exposure to peer support.
6. Preparing patients to respond to other people's reactions to the diagnosis and practising how to inform work place/studies about their diagnosis.
7. Inviting significant others to take part in consultations to address any concerns and equip them for further support.

Model 3: Phasic learning

In adapting to a life with diabetes the narratives suggest that patients have multiple learning needs as they seek to gain: an understanding of diabetes; the knowledge and skills necessary for living with diabetes; strategies for accommodating diabetes within their daily lives; and a way of considering more existential questions on what diabetes means to them. The narratives also show that patients experience multiple levels of learning and employ different learning styles at different time points.

This model expresses the learning processes and styles that occur within patients' adaptation. The model relates these to some of the key factors that inform their learning approach and how competency based learning influences their behaviour and psychological orientation to diabetes. From the narratives it seems that a key aspect of

their approach is the temporal aspect of learning. To begin with, patients have to learn to understand the language around diabetes, both in regard to the technical terms and to the pathology. While initially patients prioritise getting information about their illness and how to manage the treatment of it in order to stabilise their condition and feel safe, their needs quickly change to focus more on how to accommodate diabetes in their day-to-day lives. However, the support they receive may not always reflect this transition, as health care professionals may continue to emphasise the technical learning with a focus on glucose regulation rather than the practicalities of doing this in their daily routines. Their learning experience is also influenced by the honeymoon period. For some this is lived out like some kind of 'honeymoon war' as they wait for the real thing to start. Stepping the learning support provided to patients to reflect the varied experience of the honeymoon may be useful. Hence, following diagnosis it is important to explain to patients that adapting to diabetes is an ongoing process that is not finished after the first three years of living with diabetes. Empowering patients with self-management skills and the skills to access help in a constructive way to help them build positive adaptive strategies seems to be important. Attending to the challenges they will face by employing participatory and patient-centred approaches could be a useful model for the educational support provided for patients in the early experience of the disease. Table 5 on the next page illustrates the learning needs at various time points that occur following their diagnosis.

Table 5 Learning needs following a diagnosis of type 1 diabetes in adulthood

Aspects and phases of learning	The acute phase/the diagnostic phase	Building routines/ the adaptive phase	Synthesised learning/integrative phase
Technical/ biomedical (diet, exercise, dose adjustment of insulin)	What has happened to my body?	How to apply these skills routinely in everyday life situations	How to personalise the use of these skills in their daily lives to achieve and maintain autonomy
	What is diabetes (hyper and hypo)?	How to interpret results and adjust treatment accordingly	
	How to do blood glucose measurements and insulin injections	Changes around the honeymoon	
Psychological	The cause of diabetes in relation to questions like ‘why me?’	What diabetes means to people personally and how it affects their life	Clarity of what diabetes means and acceptance of it – becoming a person with diabetes
	Feelings of shock and anger	Grief and sadness	
Social	How to deal with other people’s reactions to the diagnosis	How to negotiate family and work life as a person with diabetes	How to engage with others as a person with diabetes

The narratives also identified that patients use both formal and informal approaches to learn about diabetes. The formal source of information available to patients is the health care system where they are exposed to one-on-one consultations and some are offered group-based education such as DAFNE (UK) or carb-counting courses (DK). The informal sources that patients actively have to seek out themselves are peers, social media and web-sites. Within these different sources various styles of learning are used.

A didactic or instructive style is used to teach patients facts about how to do blood testing and insulin injections as well as providing information about food content. However, for patients to learn what this means to them and how they can best apply these skills in their day-to-day lives a participatory approach is needed as they engage in experimental and experiential learning styles. When peer support is available imitation could also be used as a learning style. From the narratives it seems that offering various sources of information and styles of learning may positively influence patients' adaptive processes.

In this model it is possible to see how the education and self-management support provided to patients at particular phases and the learning styles of patients may be constructed to attend to different challenges they can face in the adaptive process.

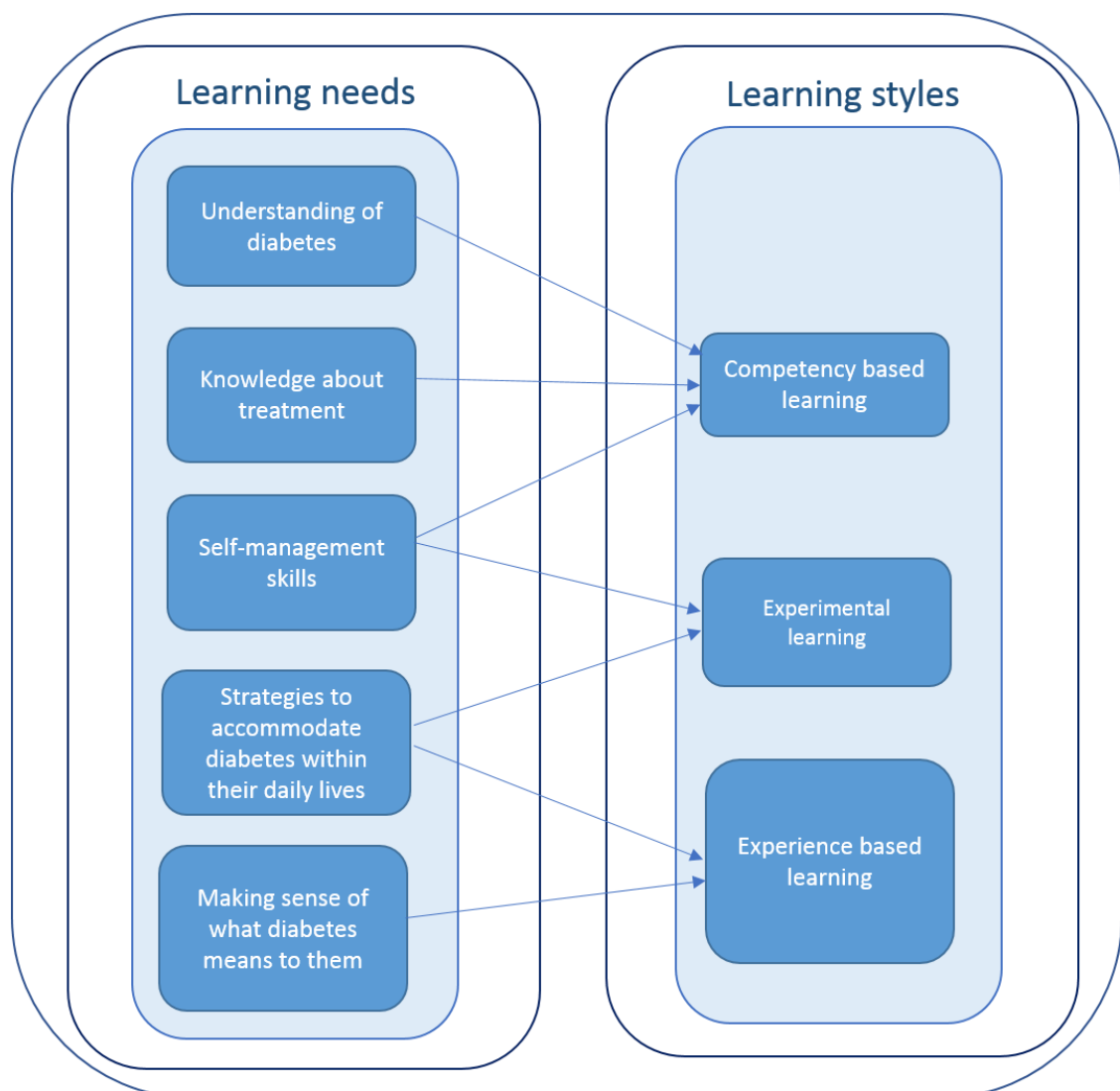


Figure 7 Phasic learning

Educational interventions in this early phase may be enhanced by considering the following:

1. Model educational support to attend to the different dimensions of diabetes learning (biological, psychological and social) and the common experiences of the disease both now and in future.
2. Encourage patients to develop self-directed learning skills with access to responsive resources that will help them develop positive adaptive strategies.
3. Use blended models of educational provision that reflect the different learning needs (bio-psycho-social) and styles (directed and experiential) of patients.
4. Provide participatory educational support to equip patients with the skills necessary to ensure that they get what they need during their interactions with health professionals (this may also require that health professionals have education so they know how best to support patients in their early disease experience).
5. Build information exposure following patient need and ability to process rather than overwhelming them with too much information at any one time.

Model 4: Health care support

This model identifies key features of the patients' experiences of the health care support that is delivered in the context of the initial phase of their life with diabetes. The narratives demonstrate several important features that define the participants' care experience which may have a significant influence on their adaptive process. The key and interlinked features of that experience that were identified in the narratives that are expressed in this model are accessibility, continuity, and communication.

Within the narratives it was suggested that the health care support was not always accessible when it was needed by patients. During the early phases of the disease patients can experience lots of events that create uncertainty, such as unpredictable glucose levels or hypoglycaemic episodes. When these happen, patients are often on their own, as they can occur at any time. In such situations patients need some support or instruction as to what to do. In consequence, they learn how to manage this

themselves. This can lead to avoidance behaviours such as running their glucose levels high, whereas others may seek expert advice which may or may not be available. Therefore, patients may benefit from being able to access some level of guidance (e.g. generic self-help materials) or knowing where they can get prompt support from a health care professional. The latter aspect needs clarity for patients as to the mechanism for this and the circumstances in which it is appropriate to seek this help.

Continuity of care and communication style were important features in the narratives in relation to the relationships they had with health care professionals. A common source of frustration for patients was that the health care professionals they encountered often had different approaches and gave different – sometimes contradicting – messages. The health care professionals' diverse styles of communication and the extent to which they facilitated patients' participation in the consultation was also a source of frustration.

Therefore, there is a need for a common storyboard to govern health care professionals' interactions with patients to ensure there is continuity and integration of their care experiences. There is also a need to emphasise the importance of a participatory approach facilitating communication that addresses the patients' agenda during consultations and responds to both their technical and their psychosocial needs.

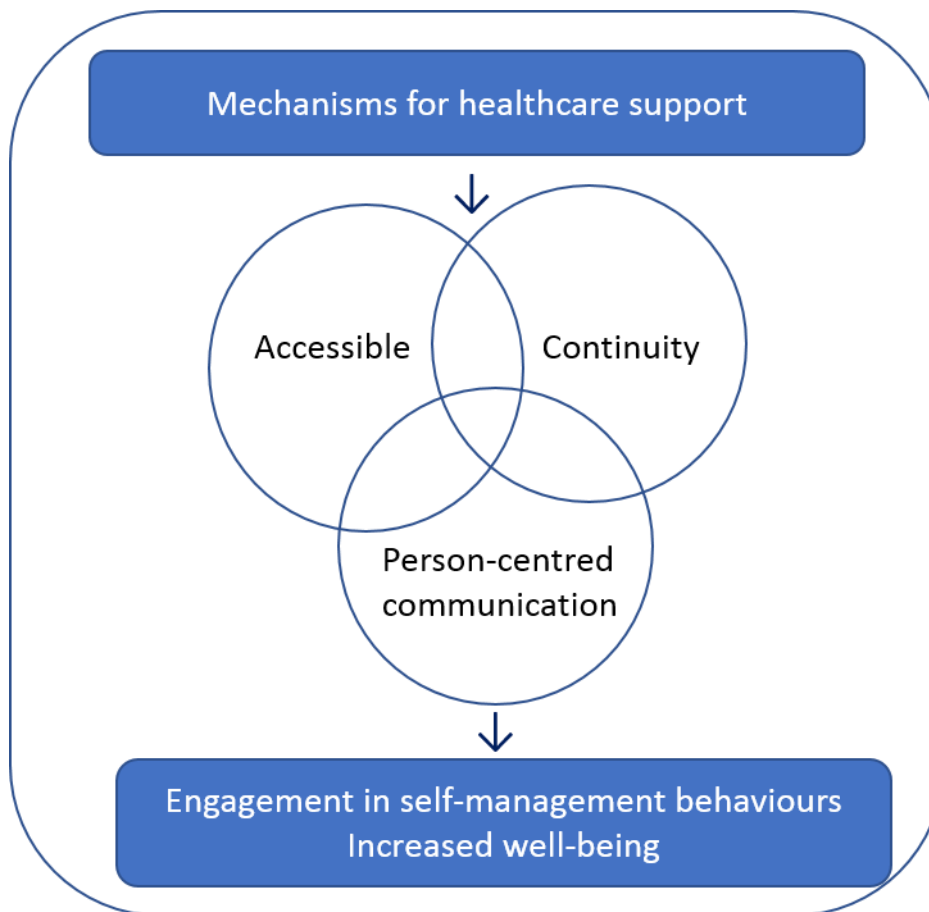


Figure 8 Health care support

From this model potential modifiable areas for intervention were identified. Future approaches could include:

1. Providing self-help resources that are accessible to patients to support them in dealing with the multiple micro-events that can inform their experience of diabetes.
2. Clearly signposting to patients so they know when and how they should seek specialist support with any particular problems that may arise with their diabetes.
3. Developing a clear pathway for adult onset type 1 diabetes that considers the bio-psycho-social needs of patients within a process of adaptation, with the aim of fostering positive adaptive strategies.
4. Ensuring that health professionals have training in the application of the care-pathway and the supportive systems and education available for patients.

5. Training health care professionals in participatory approaches where they elicit and address the psychosocial needs of patients in their consultations, such that they can respond to these needs or identify additional resources for patients.

Model 5: The glucose experience

This model formulates the participants' views and experiences in relation to regulating their glucose levels. It expresses the relationship between the reality of their experience and their perceptions of their own and others' expectations of optimal glycaemic regulation. Key features of the model are the way that health care professionals express their expectation to patients of reaching narrow glucose targets and the emotional responses that occur in patients when their blood glucose levels do not behave as they anticipate and when they do not achieve the levels expected. The emotional responses that occur such as frustration and a sense of failure can influence their health behaviours and engagement with health care professionals. In consequence, some patients avoid testing their glucose levels both to prevent the personal disappointment they may feel and to conceal them from health care professionals when reviewing their diabetes regulation. The response of health care professionals to the patients' performance in glucose regulation and how that fits within the diabetes care provided seem to be very influential in how they relate to their diabetes. The way that glucose targets are expressed to patients and incorporated into the clinical and educational dialogue may inform the mechanisms that govern how they identify and integrate diabetes into their lives and their activation of self-management behaviour. Not only does a failure to achieve targets lead to frustration, but it can also increase their exposure to hypoglycaemia as they try to meet these ideals.

The model also highlights the hazards that patients experience when their glucose levels hit more extreme parameters, in particular their exposure to hypoglycaemia. The narratives show how such episodes early in their diabetes careers can quickly lead to patterns of fearful thinking toward hypoglycaemia and avoidance behaviours. Similarly, high glucose levels also generated negative thoughts and behaviours. There was an emotional response to unexplained high values and ongoing anxiety related to the

longer-term consequences of elevated glucose levels in relation to diabetes complications.

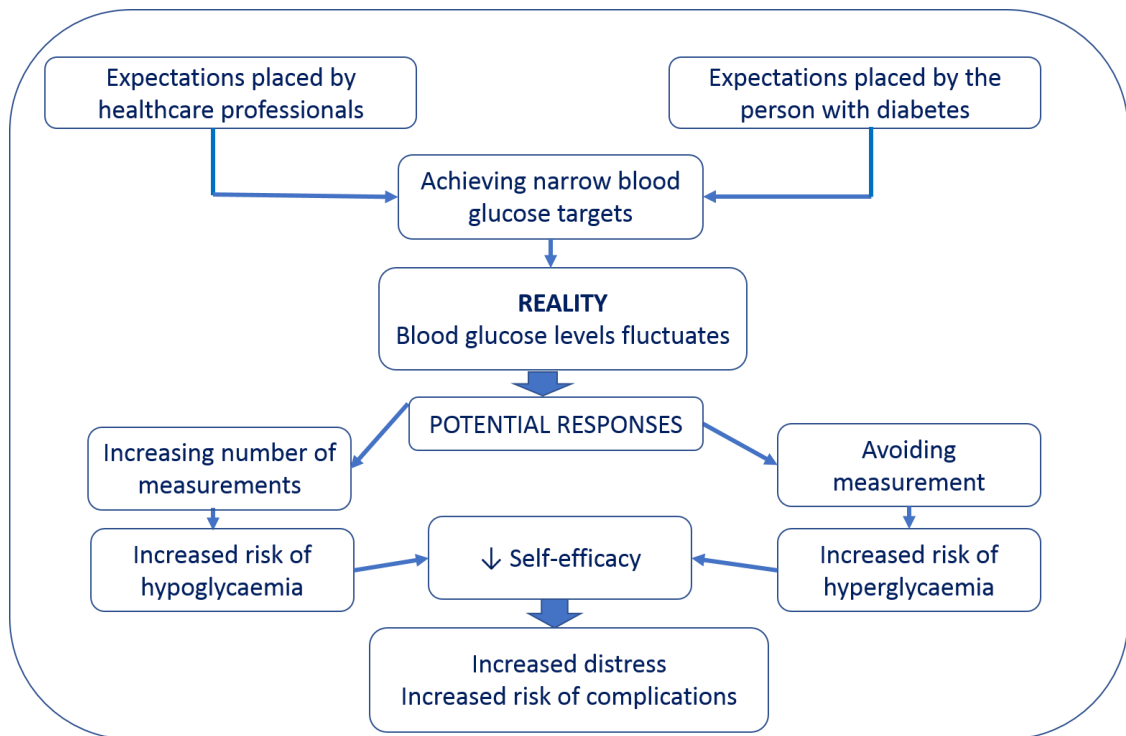


Figure 9 The glucose experience

Overall the model emphasises the plasticity of this early phase of adaptation to a life with diabetes, with many unhelpful behaviours potentially becoming habituated. It may be that intervention in this phase to help patients understand and respond to these challenges may reduce more chronic problems such as fear of hypoglycaemia or fear of complications. The study identified that future approaches need to:

1. Provide a fuller account of the complexity and unpredictability of diabetes in relation to regulating glucose values (this links with model 2).
2. Normalise the difficulties of regulating blood glucose values and help patients learn how to anticipate and manage these variations. Create a positive context for glucose regulation that does not impose expectations that may create feelings of failure.
3. Use participatory approaches to encourage and discuss experiments so patients can personalise how they want to manage their diabetes (linked to model 3).

4. Explore participants' perception of hypoglycaemia and hyperglycaemia in conjunction with reviewing their glucose levels in clinical consultations so that their potential fears may be addressed.

Model 6: Social relationships and interactions

From the narratives it is evident that a person's adaptation to a life with diabetes is impacted by their interaction with others. Such interactions affect how they construct their identity as a person with diabetes and can influence the way they enact their self-management practices. This model expresses how social relationships and patients' experiences in the social world shape their adaptation to diabetes. The model is built around the three interrelated factors that were identified in the narratives: patients' identification with diabetes in social contexts; their perception of how other people view them; and the responses of other people to them.

A common experience expressed in the narratives is how participants express themselves as a person with diabetes when engaging with others. Their own perception of what diabetes is influences how confident they are in what and how to communicate openly about their condition. If they find diabetes very intrusive or if they are not confident in managing it they may avoid talking about their diabetes. They may also curtail self-management practices because of fear of social stigma and embarrassment in the things that surround them in the context of their life with diabetes. This may have a negative impact on their relationships as they feel they have to conceal part of their life and play a role where diabetes is not visible. Patients who are more confident in their management of diabetes may express themselves more openly as a person with diabetes including informing others about their needs.

From the narratives it seems that other people's reactions can be very important in determining how much they reveal about their diabetes. If other people express their concerns for patients' health and safety in a patronising or judgemental way, patients may decide to reduce the amount of information they give to others. Patients may also be concerned that being too open about their diabetes may inconvenience others and change the way others perceive them. While it may be deemed appropriate that the

person should have autonomy over how much they reveal about their diabetes, this can become a hazard if the extent of concealment constrains their opportunities to perform their diabetes routines. Therefore, patients need to be mindful of this potential trap and be supported in developing skills and strategies to ensure they maintain the balance between their right to privacy and their right to be able to attend to their diabetes without prejudice. It may also be important that patients are confident to express themselves in different social relationships including personal, romantic, friendship and workplace relationships, as each have different nuances. Hence, considering patients' social relationships and interactions in consultations and when designing educational interventions may be important in supporting them in the adaptive process.

The model also identifies the potential benefits of personal relationships. Those that are closest to the patient will also be affected and will develop their own adaptive responses. These responses may formulate behaviours that can help or unintentionally antagonise the patient's own adaptation. This would seem to emphasise the importance for involving significant others in learning about diabetes in harmony with the patient to enhance the potential quality of the support provided in that relationship.

A fundamental aspect of this model relates to the confidence the patient has in communicating about their diabetes and their personal needs. Not only does this relate to informal social interactions such as family, friends, employers and the wider public, it also includes interactions with health care professionals as highlighted in previous models.

A final consideration might be the need to help patients realise that they may experience degrees of prejudice, stigma and misunderstanding in their interactions with others. This can be both real as reflected in the attitudes and behaviours of people or felt internally as a sense of discomfort in some situations such as what to do when dining in a public place. Therefore, patients may benefit from discussing how to negotiate these common social situations in ways that allow them both to feel comfortable and to enact their self-management behaviours according to their choice.

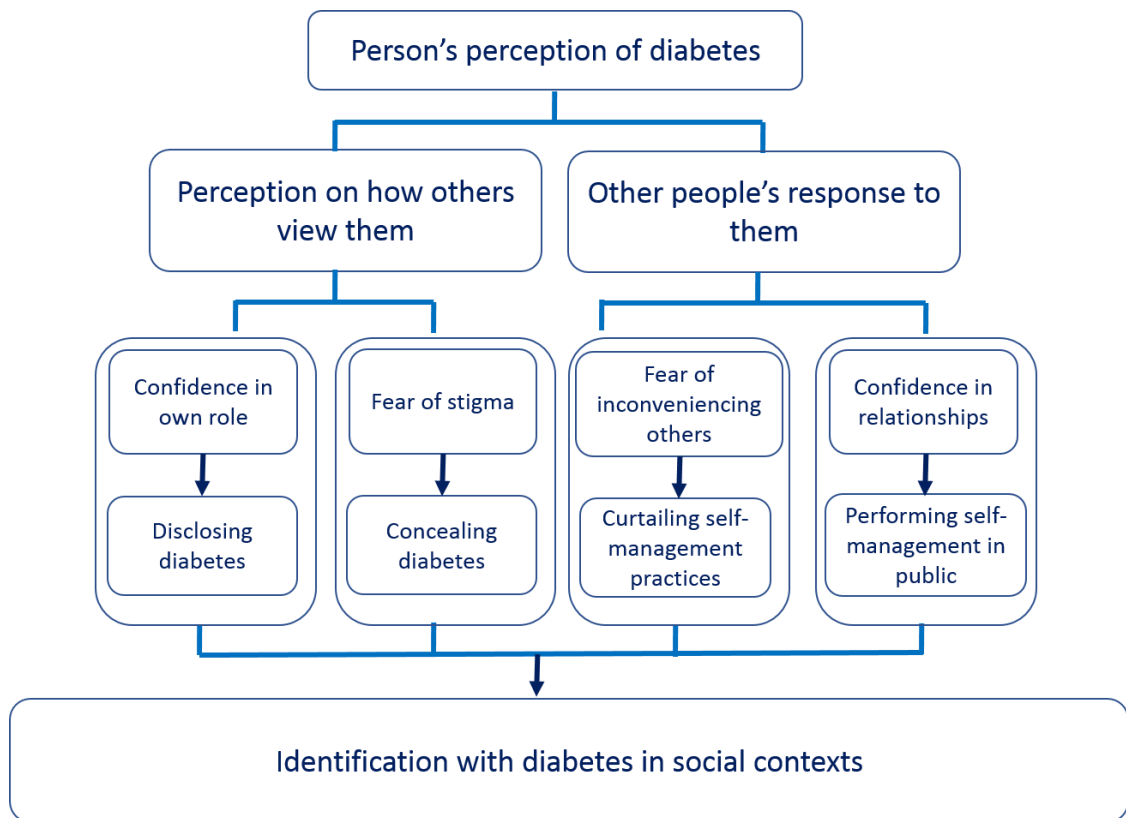


Figure 10 Social relationships and interactions

From this model potential modifiable areas for intervention were identified. Future approaches could include:

1. Highlighting the ways that social interactions and relationship can influence how patients enact self-management behaviours and how they relate to their diabetes.
2. Preparing patients for other people's reactions and equip them to respond in a way that they find helpful.
3. Encouraging patients to practice ways of communicating about diabetes and ways of telling others that they have been diagnosed with the condition.
4. Focusing on developing communicative skills that will enable them to be open about diabetes to foster supportive relationships and enhance their adaptive process.

5. Considering the adaptive processes of the patient's significant others and provide supportive self-help materials and opportunities in consultations or education sessions, so they understand common mutual concerns/issues and learn with patients to harmonise and foster mutually supportive strategies in managing their adaptive dyad.

Model 7: Common thinking styles and cognitions

How individual participants adapt to diabetes may be influenced by underlying cognitive processes. This model identifies these common thinking processes and their impact both on adaptation and on self-management practice. While many of these thinking orientations would have formed before their diabetes as part of their general psychological character, they did express themselves in the context of their diabetes following diagnosis. The participants' narratives suggested that their initial perception of what life with diabetes is going to be like, their expectation of their own ability to manage diabetes, and other people's reactions to them were shaped by their underlying cognitive tendencies.

Common related areas of cognition were the patient's self-belief in their ability to cope with the disease and their association with themselves as a person with diabetes. Patients' thinking about their ability to cope with the changes that diabetes imposes upon them can affect how they approach their diabetes. If diabetes is perceived as something that will get the better of them no matter what they do, they are less likely to believe that they will be able to influence the course of the disease. This redirects their adaptive trajectory into the areas of denial and disengagement, with the accumulation of strategies to minimise and avoid diabetes in their routines. This can also lead to them disassociating mentally from diabetes, which can impact how they identify diabetes within themselves.

Some patients' perceptions of the potential health hazards of diabetes can lead to an amplified thinking style which drives anxiety about diabetes and its potential complications. This fear of complications can produce divergent behavioural adaptations. For some it may produce a heightened level of attention to their diabetes

such that they are preoccupied with thoughts about self-management at all times; while for others it can lead to avoidance behaviours. Both a high and a low level of engagement in the adaptive process may create frustration in patients and potentially lead to development of diabetes distress.

The narratives also suggest that patients' thinking can be overwhelmed by a perception of failure. This sense of failure can dominate their thinking processes even in this early phase of the disease. As exemplified in the model on the glucose experience, this thought can be driven by the expectations placed on them by health care professionals and their struggles to regulate and stabilise their glucose levels. This can lead to low self-efficacy and feelings of frustration, with negative behavioural consequences.

Not all of the thinking exhibited in the narratives was negative. The younger participants gave examples of how diabetes catalysed a transition in how they viewed their personal health. Hence, emphasising how diabetes can be repositioned as providing some opportunities for a healthier lifestyle may be helpful to patients in identifying ways of adjusting to a life with diabetes.

Finally, the narratives reveal that emotional (feelings of anger and guilt) and existential (feelings of grief and loss) thinking influence how they adapt to diabetes. These reactive thoughts can influence both their identification with the disease and their engagement with their diabetes. While some of these thoughts are transient they can be more enduring, and when patients are pre-occupied with these thoughts they may be less orientated to their diabetes self-management practices. This, in turn, can compound feelings of frustration and a reluctance to accept diabetes in their lives.

Overall it would seem that these different thinking styles are developed very early in the process of adaptation. It may also be that patients can become trapped in cycles of negative thinking, to the detriment of their psychological and physical well-being. The accounts also suggested that these thinking processes were not routinely considered by health care professionals and often remained hidden within the patient's personal experience.

Therefore, it is necessary to be aware of how patients' thinking styles may influence how they engage in adapting to a life with diabetes. There is also a need to make

patients' thoughts about diabetes and about themselves as a person with diabetes explicit so that they can be dealt with if they are impacting negatively on the adaptive process and their well-being.

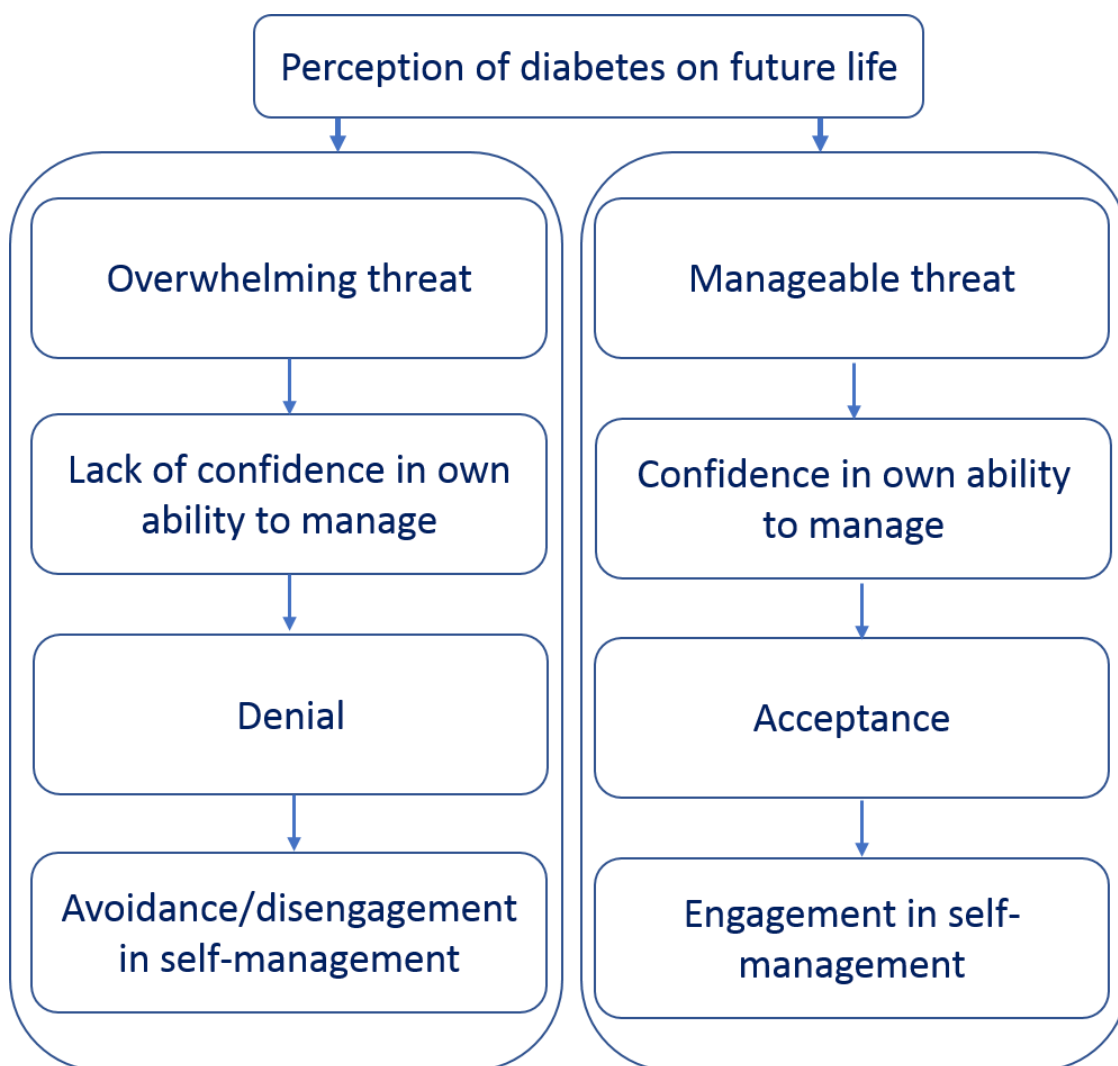


Figure 11 Common thinking styles and cognitions

When considering future interventions, the research identified the need to

1. Consider and make explicit the common thoughts about diabetes and about themselves as a person with diabetes they may experience from the onset of the condition.
2. Identify and discuss how these thoughts may influence their adaptive process (linked to models 3, 4 and 8).
3. Develop strategies to help patients recognise and deal with negative thinking patterns.
4. Ensure that health care professionals have adequate training in eliciting and addressing thought patterns (linked to model 4).

Model 8: The adaptive process

This model outlines the key phases that shape patients' adaptive process following their diabetes diagnosis. Patients' experiences of these phases will be unique, but the data suggest that there might be common experiences within the process. The underpinning construct in this model is the recognition that adapting to diabetes is an ongoing process. The adaptive phases expressed in the patients' experiences were: transitioning from their past life experience; learning about diabetes, learning to live with diabetes; and reconciling their past, present and future in a life as a person with type 1 diabetes. These adaptive phases are distinct but interrelated and non-linear, as patients can get stuck in one phase and may move backwards and forwards between phases throughout their process of adaptation.

The narratives suggest that in the initial phase, when transitioning into their life with diabetes patients experience a sense of loss and grief over their past life that instigates feelings of uncertainty as they do not know what this means for them. They need positive reinforcement that they will be able to manage diabetes, and help in overcoming the initial turmoil as they are reflecting on their past life and how or what diabetes means to them. In the following phase patients begin to construct their new life with diabetes as they learn how to adjust their lives to accommodate the self-management behaviours associated with diabetes. They also re-construct their sense of self as they learn how to accommodate the way diabetes influences their perception of self, their relationships, work and engagement in the wider society. During this phase patients can develop particular emotional reactions and behavioural orientations to different aspects of their diabetes. Hence, this phase may be quite formative in the development of their longer-term behavioural and emotional responses and habits. In the third phase patients recognise the enduring nature of their diabetes and that it demands continuous adaptations; they also begin to form an identity as a person with diabetes. Recognising and making explicit for patients this process of adaptation may be important in a number of ways. Firstly, in helping patients understand that they will need to make significant adjustments to their lives. Secondly, in normalising some of the emotional reactions and self-management challenges they may experience, such that they do not feel a sense of failure if and when they encounter them. Thirdly, in

supporting patients in developing positively orientated anticipatory and compensating strategies early on in their life with diabetes. From a health care perspective, the process may also be useful as it identifies the range of physical and psychosocial issues that patients may experience so they can be attended to both in routine care and in the provision of educational materials and programmes. It may be particularly important to assess the potential development of negative emotional reactions and associated unhelpful behaviours before these become habituated. There is also linkage between this model and the phasic learning model including the physiological changes associated with the honeymoon period which is influential in the adaptive process.

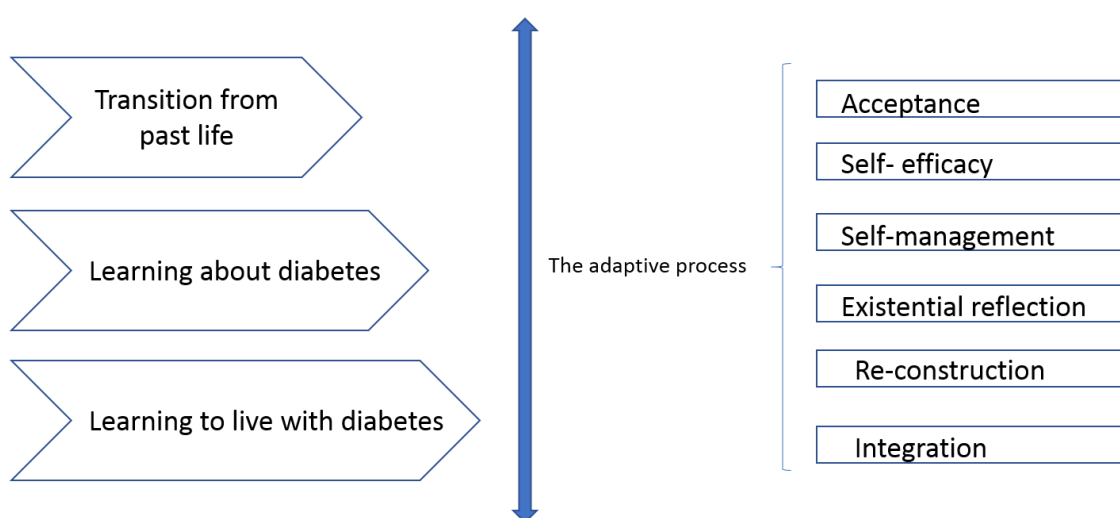


Figure 12 The adaptive process

From this model potential modifiable areas for intervention were identified. Future approaches could include:

1. Making explicit and normalising the adaptive process following diagnosis.
2. Assessing and supporting emotional and social adaptive strategies.
3. Enhancing participatory learning strategies and modelling them on the adaptive process so that they connect with the patients' experiences.
4. Focusing on developing adaptive learning strategies that build self-confidence and avoid developing a sense of failure.

5. Setting out common problems patients may encounter and providing patients with strategies to overcome these positively.
6. Recognising the bio-psycho-social aspects of diabetes in the context of their adaptation and learning, reconstructing views of the 'honeymoon period' as a period of transition with clear identification of what patients can expect and how they can manage this period of their adaptation.

Chapter summary

The models that are outlined in this chapter were developed from the participants' narratives and the findings from the meta-synthesis to identify underlying mechanisms that could potentially be targeted with interventions and care developments. They do not incorporate all the study findings but aim to capture some of the expressive relationships in the process of adaptation where future intervention might be useful. Other findings may be drawn on in developing the models further to provide other learning reference points. In addition to the figurative expression of each model, suggestions regarding alternative ways to approach care delivery to adults with new onset type 1 diabetes were outlined. However, the models, the identified modifiable areas for intervention and the suggested new approaches to care need to be further explored in detail in collaboration with people with diabetes and health care professionals to gain leverage for an improved set of outcomes for adults newly diagnosed with type 1 diabetes. In addition to bio-medical measures, such outcomes may include quality of life, well-being and social integration. It will be particularly useful to involve patients and health care professionals in co-designing any interventions to optimise their approach, format and content. The models illustrate that multi-levelled intervention is required both systemically and at a patient centred level. There also needs to be an emphasis on participatory approaches in order to develop a common frame of understanding, learning and adaptive support between patients, their significant others and health care professionals.

Chapter 7 Discussion

This study has identified a wide range of physical, psychological and social adaptations that occur following the onset of type 1 diabetes in adulthood. It is clear that the adaptation that occurs in this early phase of the disease leads to the formation of significant and potentially enduring cognitions and behavioural habits that affect the person's approach to a life with diabetes. While in some ways this is not surprising given the complexity of living with type 1 diabetes, it indicates the need for more progressive intervention in this formative phase of the disease to foster more positive adaptive strategies to prevent longer term problems. The study has also shown that adults who develop type 1 diabetes have distinctive needs. While these needs are unique to each individual, the processes involved are common and were observed in both of the national populations studied. In this chapter the findings of the study are discussed considering their contribution to current knowledge, theory and practice in relation to the care and management of new onset type 1 diabetes in adults. The chapter is organised as follows:

1. Discussion of research findings in relation to patients' experiences of the diagnosis and the following adaptive processes;
2. Strengths and limitations of the research;
3. Practice implications and directions for future research;
4. Conclusion.

Research findings

The study sought to develop a better understanding of views and experiences in a diverse sample of adults diagnosed with type 1 diabetes within the previous three years in relation to their diagnosis and their future life with diabetes. The study also set out to explore bio-psycho-social phenomena and mechanisms underlying the early process of adapting to life with diabetes, to inform the development of intervention strategies that would augment their early adaptive process as they form their future life with diabetes. The aims of the study were achieved through reviewing and synthesising the current literature in a meta-synthesis followed by a qualitative longitudinal exploratory

study. The key significant observations that have resulted from the study are critically discussed below in the context of previous studies and related theoretical perspectives.

Disruption and consequent psychosocial formations in adapting to a life with diabetes

With respect to exploring the experience of a diagnosis of type 1 diabetes in adulthood, the narratives clearly identified that the diagnosis is experienced as a disruption to habitual life. The uniqueness of this experience when compared to any other life events was profound. The perceived disruption following the diagnosis is consistent with other studies of the impact of chronic disease. Bury (1982), for example, identified the diagnosis of a chronic illness as a 'biographical disruption'. In Bury's study of 30 adults recently diagnosed with Rheumatoid Arthritis, he described the unfamiliar bodily symptoms as the starting point of the disruptive experience, leading to a re-thinking of self-concept and the recognition of an altered life situation. Previous studies have also highlighted the emotional responses that occur following the development of a chronic illness. These anxieties relate to a sense of uncertainty following a changed life situation and future life prospects (Adams et al. 1997, Cedraschi et al. 2015, Mollerup et al. 2013, Aujoulat et al. 2007, Frank 2013). While these phenomena were also evident in the narratives of the adults with type 1 diabetes, many of these feelings were amplified and accelerated by the urgency of initiating medical treatment and their need to learn a range of new self-management practices in a very short period of time. Hence, the introduction of type 1 diabetes to someone's life trajectory results in a more ferocious disruption than may be observed in relation to other chronic illnesses such as type 2 diabetes, where the process develops more slowly (Hörnsten et al. 2011, Lo and MacLean 2001). The findings of this study show that the ferocity of this disruption has a major impact on the person's psychological well-being and that many of the emotions associated with it can remain unresolved, at least in the first three years after diagnosis. Furthermore, the study has identified that these negative formations in relation to the disrupting effect of diabetes were not attended to adequately in the participants' care experiences as illustrated in models 1 and 2 in chapter 6. This failure to attend to the emotional consequences of the disruption that occurs with diabetes

concur with the findings in other studies that this may potentially cause longer term psychological distress (Fisher et al. 2010, Fisher et al. 2015, Pallayova and Taheri 2014). However, this study suggests that many of these problems gestate in this early disruptive period, indicating the need for early attention from all members of the multidisciplinary team to support a more constructive psychological framing for adults with type 1 diabetes from diagnosis.

In the meta-synthesis of previous studies presented in chapter 2, a number of psychosocial phenomena and reactions to the disrupting effect of diabetes were identified. These included significant impacts on self-identity and role performance in social contexts. For example, one study included in the meta-synthesis highlighted the confrontation between diabetes and identity that followed from the diagnosis (Goldman and Maclean 1998). Other studies underlined the challenges of interacting with others as a person with diabetes (Everett 1999, Johansson et al. 2009, Pender 2010, Smith 2010). In addition to these previous observations, this study has shown a number of new features in relation to psychosocial effects of the diagnosis. Firstly, that the disruption creates enduring negative emotional reactions; and secondly that the disruption itself also changes through time. The narratives showed that the experience of disruption changes from the initial profound reorientation demanded by the presence of diabetes, to a series of micro disruptions. These micro disruptions are expressed in the daily demands of diabetes self-management. Hence, disruption in this chronic form is distinct from the initial disruption, but like the first phase of disruption it also generates negative emotional orientations. In their ethnographic study on self-management Hinder and Greenhalgh (2012) identified a wide range of practical tasks linked to self-management practices that potentially create multiple cognitive, emotional and social interruptions on a daily basis. These continuous disruptions are unique to diabetes and may maintain and exacerbate the negative emotional reactions towards diabetes. Ongoing disruptions may also be experienced in other chronic illnesses, though not usually on a daily basis, but rather in episodes when their illness flares up, such as in conditions like Irritable Bowel Syndrome (Weinland et al. 2011) or hand eczema (Diepgen et al. 2007). When considering disruption in relation to a

diagnosis of type 1 diabetes in adulthood, this study corroborates Whittemore and Roy's (2002) theory of 'adapting to diabetes mellitus'. The study showed that being diagnosed with type 1 diabetes in adulthood can be considered a major event as expressed in their theory and, as they identified, this influences the individual's perception of their illness and subsequently their adaptive response. However, this study adds understanding to this process by distinguishing the acute and chronic forms of disruption. Furthermore, it suggests that the processes may be more complex than previously suggested, with the force of disruption and the person's response to the disruptions being integral to adaptation rather than just stimuli for it. Therefore, it seems important to consider how the initial disruption as well as the more chronic forms of disruption affect adaptation to life with diabetes when supporting adults recently diagnosed with the condition.

Bio-psycho-social and adaptive processes following diagnosis

Another objective of the study was to explore underlying bio-psycho-social phenomena and mechanisms in relation to the early process of adapting to life with diabetes. The study reveals that there is a high level of interconnectivity between the physical, psychological and social aspects involved in adaptation. Previous qualitative studies of adults with longer duration of diabetes have highlighted many elements of these phenomena, such as: the complexity of managing hypoglycaemia (Lawton et al. 2013, Lawton et al. 2014, Nafees et al. 2006), structuring everyday life to accommodate diabetes self-management (Maclean 1991, Price 1993, Rankin et al. 2012, Ridge et al. 2012, Rintala et al. 2013b, Balfe et al. 2013), understanding diabetes (Hernandez 1996, Ingadottir and Halldorsdottir 2008, Paterson et al. 1999), decision-making (Paterson et al. 1999, Paterson and Sloan 1994, Zoffmann et al. 2008), impact on relationships (Trief et al. 2013, Sato et al. 2003, Rintala et al. 2013b, Rintala et al. 2013a), work (Burda et al. 2012, Balfe et al. 2014, Akhtar et al. 2016), and accepting diabetes (Ryan and Coates 1998, Nyhlin et al. 1987, Stuckey and Tisdell 2010, Hartrick 1998, Due-Christensen et al. 2006). However, the unique feature of this study was that it sought to understand the bio-psycho-social features of the early disease experience of diabetes in an integrated way and from the perspective of adaptation.

The bio-psycho-social framework as outlined in chapter 2 stressed the importance of having a broad concept of health (Engel 1977, WHO 1998), incorporating social, psychological, biological and behavioural aspects when understanding what it is like to live with a chronic illness. Whitemore and Roy's theory of 'adapting to diabetes mellitus' also adopts a broad concept of health, as they identified the physiologic and psychosocial processes involved in adaptation corresponding to the bio-psycho-social framework (Whitemore and Roy 2002). In their model they also highlight the interconnectivity between the physiological and the psycho-social adaptive responses. It is clear from the study data that the patients' experiences involve a wide range of different bio-psycho-social elements that interplay with each other shaping their behavioural responses. The main bio-psycho-social phenomena observed in the study are explored in more detail below.

There are many biological factors that become highlighted following a diagnosis, with the individual's need to actively regulate their glucose metabolism being the most overt. While, this is a self-evident requirement of a life with type 1 diabetes as reflected in previous studies (Grant et al. 2013, Berkeley et al. 2012, Araskiewicz et al. 2008, Shaban et al. 2013), this study shows that this requirement rapidly becomes overlaid with other factors such as: the daily challenge of maintaining a stable blood glucose, the experience of hypoglycaemia, periods of hyperglycaemia, and the understanding of the potential long term complications if they fail to tame their biology. Such factors seem to trigger emotional reactions such as diabetes distress and may also lead to negative behavioural habits and social consequences.

The honeymoon period

A key observation from the study, highlighting a biological aspect of the transition into a life with diabetes, was the experience of the honeymoon period. While current research on the effects of the honeymoon typically emphasises the physiological benefits such as stabilisation of blood glucose values and fewer incidences of hypoglycaemia (Oram et al. 2014, Kuhlreier et al. 2015, Barker et al. 2014), this study

suggests that from the patients' perspective this period is double sided. A novel finding in the study was patients' negative perception of the honeymoon period, conferring additional uncertainty and adding to their emotional burden in processing what the disease will eventually bring to them. The study highlighted how the health care professionals failed to understand the way participants felt about the honeymoon and tended to promote it as a positive phase in regard to insulin management. The participants expressed a need for more detailed information on the honeymoon and better emotional support during this period. Hence, health care professionals need to be mindful that their view of the honeymoon and that of the patient may be divergent as outlined in models 3 and 8 in chapter 6.

Achieving blood glucose targets

Another area where a biological parameter has a big impact on the person's psychological well-being and health behaviours is blood glucose. Current practices place a high emphasis on the importance of achieving particular glucose targets to reduce the risk of developing complications (DCCT 2016, Pirola 2014). Health care professionals internalise this message which is reinforced by current clinical guidelines and targets (NICE 2015, Danish Endocrine Society 2016), such that it becomes a major preoccupation and receives disproportional attention in clinical interactions with patients. The study data have shown that many patients find the constant focus on glycaemic targets oppressive, and for many it engenders a sense of failure even if their HbA1c is within the target range. From the patients' perspective there is also a sense that attaining and sustaining these targets is too demanding. This observation resonates with work of Snow et al (2014) and Kay et al (2009) who found that adults who did not reach these specific targets blamed themselves if their self-management efforts were unsuccessful. Snow (2013) observed that in some cases this could lead to demotivation with negative consequences in the long term (Snow 2013). Other studies have also shown that patients may compensate for this by adapting the targets upward, so they are more comfortably attained, increasing their risk of diabetes complications (Rankin et al. 2012). On the other hand, Rogers et al (2012) observed in another qualitative study that some patients overestimate the impact of high values

due to a fear of complications, leading to recurrent episodes of severe hypoglycaemia. This behaviour has also been observed in a Chinese sample (Shiu and Wong 2002). These adaptive patterns were also observed in this study and in addition, the patient narratives suggest that these behaviours brought negative consequences for their job performance and created anxiety within their social relationships. These negative social consequences of hypoglycaemia have also been identified in previous studies (Lawton et al. 2014, King et al. 2015, Polonsky et al. 2016). In line with this, a disturbing finding in this study was that even in an early stage of life with type 1 diabetes, some had developed hypoglycaemia unawareness due to their consistent endeavour to maintain a low blood glucose level which was related to their fear of developing complications. While hypoglycaemia unawareness has been explored in studies involving adults with longer duration of diabetes (Lawton et al. 2014, Lawton et al. 2013, Rogers et al. 2012), this is the first time it has been reported specifically in the adult onset population. This finding may be of high importance as it suggests that there may be a need for much stronger intervention in the early formative period before these behaviours and the emotions that drive them become habituated.

Collectively these findings again illustrate the interconnectivity between the biological aspects of diabetes (e.g. lowering the blood glucose values, having recurrent hypoglycaemia) with the psychological (e.g. fear of complications) and social aspects (e.g. work performance and relationships) of the disease. This connectivity has also been identified in previous studies involving adults with longer duration of diabetes (Nyhlén et al. 1987, Maclean 1991, Ingadottir and Halldorsdottir 2008, Paterson et al. 1998, Paterson et al. 1999, Lundman et al. 1988). This may indicate that in providing care early in the treatment of the disease, greater consideration needs to be given to this interplay; and perhaps more fundamentally there is a need to recognise that fixing the biological processes will require more than imparting technical skills to the patient. The findings in relation to these biological parameters resonate with Whittemore and Roy's theory (2002) in that they confirm the interplay between the stabilisation and psycho-social integration phases of their model. In Whittemore and Roy's model it is inferred that the perception of illness is a driver for adaptation. However, the findings

suggest patients' perception of their diabetes can also change as a consequence of their experiences with adapting to diabetes. This is particularly evident in the patients' experiences of living with diabetes and their learning through which they discover new insights into the nature of the disease and its impact on them. This churn of experience and diabetes identification can create tensions in the individual which become manifest in how they perform their self-management behaviours. Again, this emphasises the need for a multifaceted approach to care support from the onset of the disease attending to biological, psychological and social reactions induced by the condition in proportion as suggested in models 2, 3 and 8 in chapter 6.

Learning about and learning to live with diabetes

The participants' narratives highlight the significant role played by the need to accommodate self-management in their adaptive trajectory. Patients need to make considerable adjustments and additions to their daily routines following diagnosis. These adjustments had distinctive impacts on both their emotional orientation to the disease and their interactions within their social world. The significance of self-management education and learning about diabetes is well established within the care of people with diabetes generally (Amiel et al. 2015, Coates and Boore 1996, Lorig and Holman 2003, Price 1993, Reddy et al. 2016, Colagiuri and Eigenmann 2009) and also in those recently diagnosed with the condition (Audulv 2013, Audulv et al. 2012, Everett 1999, Johansson et al. 2009, Pender 2010, Shaban et al. 2013, Araszkiwicz et al. 2008, Kneck et al. 2012). While there seems to be a recognition that self-management education must provide skills in treatment of the disease as well as addressing changing roles and the emotional impact of having a chronic condition (Lorig and Holman 2003), many programmes underplay social and psychological issues within their curricula (Araszkiwicz et al. 2008, Berkeley et al. 2012, George et al. 2008, DAFNE Study Group 2002). Research into self-management has increasingly acknowledged the emotional and social burden attached to these practices. However, this study illustrates how the burden of self-management is felt very early following the diagnosis as patients try to accommodate diabetes within their everyday lives. This finding resonates with previous quantitative studies on the adult new onset population

identifying high levels of diabetes distress (Reimer et al. 2016) and psycho-social challenges (Kampling et al. 2016, Taylor et al. 2003, Rane et al. 2011, Spiess et al. 1994) during the first years of living with diabetes. The findings in this study revealed in-depth information about patients' experience of this burden. While patients recognised the importance of learning the technical skills, they found it demanding but straightforward. In contrast, gaining the confidence to enact these skills within their social contexts was perceived as challenging and burdensome. The study identified that the emotional and social challenges of enacting self-management behaviours within patients' social worlds did not receive much attention from health care professionals. The health care professionals' predisposition to focus on technical, instrumental or behavioural aspects of self-management education is consistent with findings in other studies (Entwistle et al. 2016, Sadler et al. 2014, Kay et al. 2009, Burda et al. 2012, Ruston et al. 2013, Mol 2009). Furthermore, this study has highlighted the distinct but highly interrelated processes of learning about diabetes and learning to live with diabetes. This involves recognising the uniqueness of diabetes in terms of its enduring and all-encompassing nature; the influence diabetes has on their perception of self, their relationships, work and engagement in the wider society as suggested in models 2, 3, 6, 7 and 8 in chapter 6. If these aspects of living with diabetes are not attended to early on, negative perceptions about life with diabetes may become embedded to the extent where it is difficult and challenging to reshape or transform them. It may also lead to poorer outcomes in the long term, something which is evident in the current large number of adults with longer standing type 1 diabetes with an elevated HbA1c level (McKnight et al. 2015); who experience diabetes distress (Sturt et al. 2015, Zoffmann et al. 2014, Schmitt et al. 2014b, Mohn et al. 2015); or have comorbid depression (Barnard et al. 2006, Lloyd et al. 2012). In an attempt to reverse these poor outcomes many current psychological interventions have specifically targeted people with a high HbA1c (Zoffmann et al. 2015, Amsberg et al. 2009, Ismail et al. 2010, Hermanns et al. 2013, Zoffmann and Lauritzen 2006) or depression (Hermanns et al. 2015), with varying levels of success (Winkley et al. 2006, Harkness et al. 2010, Steed et al. 2003). However, many suggest that sharing experiences with others with type 1 diabetes is perceived as being beneficial by participants. While there have been some small-scale interventions that have targeted psychological issues in the new onset adult

population, (Gafvels et al. 2014, Shaban et al. 2013, Spiess et al. 1995) these studies are highly heterogeneous with mixed findings. Providing evidence in relation to interventions that are effective in targeting both bio-medical and psycho-social aspects of living with diabetes is further complicated by the fact that funding for research into psycho-social aspects has had an extremely low priority (Harkness et al. 2010). It has been estimated that less than 10% of research funding is currently allocated to studies with a psycho-social focus by diabetes associations and organisations in the UK, USA, Australia, the Netherlands and Canada (Jones et al. 2016).

However, the data from this study emphasise the need to focus equally on the bio-psycho-social aspects from the onset of the disease as it may be the failure to adequately address these early in disease adaptation that leads to the formation of longer term and potentially more entrenched negative adaptive processes and unhelpful behavioural patterns. Hence, if cognitions about diabetes and self-management behaviours were identified at this fluid stage of living with diabetes, negative thoughts and feelings towards diabetes could be attended to before they become rigid, potentially preventing diabetes distress and complications in the long term.

Making sense of the diabetes diagnosis

Another example illustrating how patients' cognitions about diabetes are interlinked with adaptation, is found in the way they influence the process of identifying themselves as a person with diabetes. The narratives have shown that patients can have powerful thoughts relating to the impact diabetes has on their lives, however, these thoughts were often unvoiced. The accounts suggested that the early phase of the adaptive process was shaped by their perceptions of what diabetes means to them in the context of their past life. This pattern of thinking has also been highlighted in studies relating to adaptation to other chronic diseases (Aujoulat et al. 2007, Kessler and Liddy, Livneh 2001, Smith and Sparkes 2008, Frank 2013). In keeping with those studies, the data from this study suggest that many people go through a grieving

process from the outset of the disease, as they reflect on the loss of their “carefree” and normal past life situation. This process can be difficult as many participants struggled to come to terms with the impact diabetes had on their lives. While they were adamant in expressing that diabetes should not be a hindrance in doing what they want with their lives, there was an underlying sense of loss in relation to spontaneity and the augmented demand for planning they now faced in contrast to those without diabetes. This process of grief and loss in relation to the limitations and implications of diabetes has also been identified in studies on adults with longer standing type 1 diabetes (Brown 1985); parents of children newly diagnosed with type 1 diabetes (Lowes and Lyne 2000); people with type 2 diabetes (Nash 2013, Phillips 2014); and people with longer diabetes duration who have encountered complications (Spiess et al. 2014). The meta-synthesis and the empirical study highlighted the threat posed by diabetes to their social and personal identities, this often led to existential reflections during which aspects of the grieving process were expressed with feelings of denial and anger towards diabetes. This pattern of grief and acceptance seems to be a common feature of chronic illness exposure as it has been observed in relation to other chronic illnesses (Telford et al. 2006, Sharpe and Curran 2006, Simmons et al. 2007, Delmar et al. 2005, Frank 2013) and cancer (Konradsen et al. 2012, Prigerson and Maciejewski 2008).

The study narratives highlighted that accepting diabetes is more than coming to terms with a changed life situation, it also entails assuming responsibility for the multiple self-management responsibilities demanded of the condition and making sense of what diabetes means to them. The data also suggested that if patients are struggling to accept diabetes they find engaging in self-management behaviours harder to adopt as they try and diminish diabetes as a part of their identity. These findings resonate with studies on other chronic diseases or longer-term diabetes identifying acceptance as essential for engaging in adaptive strategies (Ambrosio et al. 2015, Abdoli et al. 2008, Aujoulat et al. 2007, Beran 2014, Beran and Golay 2017, Lundman and Norberg 1993, Ryan and Coates 1998, Kelleher 1988). The findings of this study indicate the importance of the formative stage in relation to the person’s psychological and social

adaptation. Failure to attend to the grief reaction and to help patients formulate a positive model of acceptance in the early stages of diabetes may add to patients' negative cognitions and potentially hamper their adaptive process in the longer term. It may also lead to social isolation and an increased feeling of being burdened by diabetes. In addition, the study has highlighted that many of the challenges adults recently diagnosed with type 1 diabetes encounter in relation to identity issues are largely silenced and unaddressed in their encounters with health care professionals. While the lack of attention to psycho-social factors in consultations is not a novel finding, as it has been identified in other studies both in diabetes (Byrne et al. 2017, Peyrot et al. 2006, Stuckey et al. 2015, Pouwer et al. 2006) and in other chronic illnesses (Brandes et al. 2017, Ronnevig et al. 2009), it is perhaps surprising given the depth of the emotions voiced by the participants in the narratives in relation to their early adaptation to the disease. While there are likely to be multiple reasons for the lack of attention given to patients' psycho-social needs in the early stage of the disease by health care professionals, it may be that the emphasis within current guidelines on the introduction of diabetes therapies to stabilise blood glucose levels following diagnosis means that this becomes the primary focus (NICE 2015, Danish Endocrine Society 2016). The study has also highlighted that the diabetes discourse in clinical interactions is largely expressed in a bio-medical language with an emphasis on glucose control and targets, leaving little room for discussing emotional aspects. Previous studies in diabetes (Dunning et al. 2017, Ogden and Parkes 2013, Zoffmann and Kirkevold 2005) and heart disease (Blackman and Sahebjalal 2014) have identified how patients adopt this new medical language of their condition, a language which has a vocabulary that is biased to the professionals' agenda and may limit the opportunity to explore issues that emerge from the personal experience of diabetes. The narratives suggest that this missed communication can lead to continuing emotional distress and a person's lack of confidence in their own ability to manage diabetes, and may lead to a reduction in their health attending behaviours. This finding resonates with previous literature identifying the difficulty of confronting issues that may be hidden from one or both participants (Stelter 2000, Toombs 1993, Aujoulat et al. 2007, Frank 2013) and also the challenge of expressing emotional concerns when living with a chronic illness (D'Agostino et al. 2017, Engqvist Boman et al. 2017, Spiess et al. 1995).

In an attempt to suggest ways to respond properly to the psycho-social issues patients are faced with, the American Diabetes Association has recently published a position statement on psycho-social care for people with diabetes (Young-Hyman et al. 2016). Likewise, the Australian Diabetes Association has published a handbook on emotional health in diabetes (Diabetes Australia 2016) and a position statement on the use of language in diabetes drawing attention to the importance of how language is used when communicating with patients (Speight et al. 2012). While these guidelines also include consideration of new-onset disease in adults they still need to be incorporated into clinical practice to help alleviate the burden of living with diabetes.

While this burden is felt across the age span, this study illustrates that the changes diabetes imposes on people's sense of identity are perceived as especially burdensome by adults who are diagnosed at an older age. This finding is in contrast to the suggestions of Moos and Tsu (1977), who reported that older people have more personal resources to use when faced with a chronic illness, based on their maturity. A possible explanation for this difference may be that younger adults, when transitioning into adulthood, are going through identity development so that diabetes becomes incorporated within this development (Luyckx et al. 2008, Rassart et al. 2014, Rasmussen et al. 2007). The data also showed that some of the younger participants took a more optimistic perspective on the arrival of diabetes in their lives, seeing it as an opportunity to focus more on their personal health. Hence, while other studies have previously highlighted that patients do identify the potential benefits of diabetes in their lives (Rubin and Peyrot 1999, Thorne and Paterson 1998, Kay et al. 2009), this study suggests that such perception may differ depending on the amount of life exposure. It is, however, important to emphasise that while younger people may find it easier to identify diabetes within themselves this does not necessarily mean that the way they identify diabetes is positive as it still engenders many uncertainties and introduces stressors which can lead to emotional distress. Conversely older adults' self-identity may already be very established and less fluid than it is in younger adulthood, this may generate a stronger reaction and some resistance in how they incorporate diabetes within their personal identity. This observation concurs with other studies of

various chronic diseases which have reported that disease exposure can be met with resistance from the individual in relation to how they identify it as part of themselves (Williams 1984, Freeman 2001, Corbin and Strauss 1985, Goffman 1963).

Theoretical perspectives

From the outset of the study, adaptation and the bio-psycho-social framework were used to inform the analytical perspective of the study. The findings of the study have highlighted that the transition into a life with diabetes involves a complex range of adaptive processes. The data support the assertion expressed in Whittemore and Roy's model that health promoting behaviours are influenced by self-identification with the disease together with a range of wider psycho-social processes. However, the findings from this study provide more in-depth insights into some of the mechanisms that may inform these relationships. The study has highlighted specific details about the interaction between the characters and the settings in which the integration process occurs, it has also identified that within clinical consultations these interactions are largely silenced. In particular, existential issues such as feelings of grief and loss were not attended to, potentially adding to the burden of living with diabetes. Again, this supports the need to openly address all the challenges adults newly diagnosed with type 1 diabetes may encounter during this adaptive phase.

The study findings also support the idea expressed in Roy and Whittemore's 'adapting to diabetes mellitus' theory, that adaptation is an interrelated, dynamic and ongoing process of progressive stabilisation as the person tries to find health-within-illness. However, the study has added more details as to what aspects shape the stabilisation and integration processes, by illustrating that the pathophysiological character of the disease (such as the honeymoon) and a person's cognitive and emotional responses to it may influence the manner and extent to which the person can integrate diabetes into their lives. Congruent with the theoretical model the study findings emphasise and detail the complexity of living with diabetes and the need for a multifaceted approach to care for adults with new onset type 1 diabetes. The study findings have enhanced

the understanding of underlying bio-psycho-social phenomena that influence the adaptive process and identified modifiable mechanisms that could be influenced to help patients achieve a more positive adaptive outcome.

Study strengths and limitations

In this section the strengths and limitations of the study will be outlined. The purpose of qualitative research is to explore complex phenomena in specific contexts by obtaining rich and nuanced descriptions (Britten 2011). The amount of data needed from each interviewee to reach an in-depth understanding of the complexity limits the size of the study sample (Sandelowski 1995, Malterud et al. 2016). Bearing in mind that this study is interpretative in design and based on a purposive sample it cannot be generalised in its entirety to other populations. The transferability of the findings must, therefore, be considered in other contexts by researchers and experts in the field. When considering the transferability of findings, the context in which the data were collected and the characteristics of the participants must be taken into account. A particular strength of this study was the inclusion of several clinical settings in two countries and a relatively large and diverse group of people in relation to age and duration of diabetes. The previous qualitative studies specifically exploring the adult onset type 1 diabetes population had smaller samples with limited diabetes duration (Everett 1999, Johansson et al. 2009) and age range (Pender 2010). In contrast, this study was able to explore the experiences of living with diabetes in a wider age group and examine the disease experience during the first three years after the diagnosis. In addition, the longitudinal design afforded the opportunity to highlight important changes in the patient experience such as coming in and out of the honeymoon period. The time interval between the two interviews was restrained due to the duration of the PhD and it is possible that a longer interval would have revealed additional perspectives.

The narrative interviews provided a rich description of participants' experiences of the diagnosis and their process of adapting to life with type 1 diabetes. The narrative

approach encouraged the participants to share experiences openly in relation to their life with diabetes. The semi-structured interview guide allowed them to focus on aspects that they found important as opposed to following a structured guide that would point the interview in certain directions chosen by the researcher. The use of dialogue tools could be considered both as a strength and a limitation. They assisted participants in expressing emotional and social aspects of their experiences that they often had not previously spoken about. However, at the same time they might be perceived as directive of eliciting specific information. To minimise this potential bias, participants were made aware that the tools were only there as a guide and could be overlooked. The fact that some participants did not engage with the tools indicates that they understood that using these tools was voluntary.

This study was the first transnational study to explore adults' experiences of the diagnosis and their adaptation to life with diabetes. A compelling finding was the degree of commonality within the sample despite some differences in socio-cultural context and health care systems. The common experiences could be because of underlying similarities in the types of participants and between the diabetes centres. If the sample had involved more amplified cultures (such as between an affluent and a developing country), the findings may have been different. However, the meta-synthesis presented in chapter 2 and previous qualitative studies on long term type 1 diabetes involving samples from countries with more diverse cultural and socio-demographic backgrounds have also found commonalities in experiences of living with diabetes (Abdoli et al. 2008, Sato et al. 2003, Stuckey et al. 2014). For example, in a study involving patients with type 1 diabetes from 13 countries, Beran identified common needs across the sample in relation to survival, well-being (2014) and education (2017).

The commonalities that were identified across the two countries in relation to participants' experiences and the underlying bio-psycho-social phenomena suggest that although these are perceived differently by each individual there are universal issues that need to be attended to when caring for this population. While the findings are likely to be transferable to similar populations attending specialised clinics in

westernised societies, they may not be transferable to populations in less developed countries with different availability of health care, culture or societal organisation. In addition, the findings may not be applicable in health care systems that are fundamentally different, such as the US.

My extensive clinical experience within the field of diabetes could also be considered as both a strength and a limitation. It was previous clinical experiences that caused me to wonder about how adults who are newly diagnosed with type 1 diabetes experience the particular issues they are faced with when adapting to a life with diabetes. The flipside is that any ideas derived from my prior clinical experience might have regulated the depth of the data that were elicited in the narrative. When participants shared their story, I might in some situations have assumed that I understood the intention of their statements instead of probing for meaning in a way others with less experience might have done. On the other hand, I was able to probe even more for meaning due to my clinical knowledge which might have elicited more in-depth data. In qualitative research the collection and interpretation of data are hugely dependent on the researcher's skills and are therefore subjective and might have been different if done by another person. However, to allow for these limitations, measures were taken in regard to the conduct, the relevance and the trustworthiness of the study. In order to ensure rigour in the research process, the process was made transparent to ensure coherence between the data and the interpretation. In addition, patient advisory groups, a professional advisory group and interdisciplinary research teams in both countries were involved in the study. While the patient advisory groups were not involved in designing the study, they were included in devising the patient information and the interview guide, and were consulted as part of the analytic phase. During the course of the PhD the professional advisory group and the two interdisciplinary research teams I was connected to in Denmark and the UK respectively acted as discussion boards, challenging my assumptions and arguments. They also peer-reviewed the research process and the findings. Furthermore, the findings have been disseminated at different events and a plan for further dissemination of the research has been devised (see appendix K).

Practice implications and directions for future research

The study findings and conclusions suggest a range of implications for practice. The meta-synthesis and the empirical study have provided evidence about underlying bio-psycho-social phenomena that influence the process of adapting to a diagnosis of type 1 diabetes in adulthood. The study has also identified that many of these bio-psycho-social challenges are not attended to from the onset of diabetes within the health care systems explored in this study. The findings showed that current interventions for adults with new onset type 1 diabetes provide good support in regard to the bio-medical aspects of learning about diabetes. The curricula of these interventions could potentially be developed to incorporate support for the psycho-social needs expressed by the participants in this study related to learning to live with diabetes.

The theoretical models that are outlined in chapter 6 describing potential supportive interventions, suggest that patients may benefit from psycho-educational intervention early on to forestall the development of chronic negative emotions, and the unhelpful thinking styles and behavioural patterns that are observed in some people with more established diabetes. This would be in contrast to present practice where such interventions are generally offered only when these problems may have become more entrenched and the patient may already have developed some physical complications. The models recognise the various phases during the first three years with type 1 diabetes and suggest specific interventions throughout the various phases. It may also be important to titrate the intervention so what is required in each of these phases is reflective of the individual's needs.

In terms of future intervention, the study shows that a multiphasic and multimodal approach is required to tackle different aspects of patients' experience and their adaptive processes over a longer period of time. Therefore, it is likely that additional attention to addressing psycho-social needs in established structured education programmes for adults with longer duration of diabetes may be beneficial. The study has also highlighted the benefit of having some theoretical constructions to support intervention that map onto potential common areas for adaptation within the bio-psycho-social framework.

While the combined study findings have provided some very useful data, adding to existing theory and identifying potential mechanisms for intervention, further research is needed to develop and test the content and format of such an intervention. Development of the content and format would likely profit from following participatory and patient-centred principles as outlined in the MRC framework (2006, Craig et al. 2008). However, from the data it would seem probable that the intervention will need to develop tools to support dialogue between patients and health care professionals and between patients and their significant others. Development should also aim to contextualise the intervention with reference to patients' needs. Methods such as conducting workshops with patients and health care professionals separately or in combination may be considered when developing the intervention. The narratives have highlighted the benefits of peer support which may be one model of delivery of the intervention. In relation to evaluating the intervention, outcome measures would need to reflect the content and be able to capture differences over time. The measures used to evaluate previous programmes/interventions in the adult onset population could potentially be applicable, although these would need to be optimised during the preliminary evaluation of the intervention.

Furthermore, longitudinal studies in the adult onset population exploring the bio-psycho-social adaptive process would generate an even wider perspective on the effects of this period over time. This study sample could potentially be followed up with interviews every second year to gain more knowledge of the process of adaptation over the longer term. Moreover, additional knowledge about the adaptive processes would be gained by conducting quantitative studies, including the assessment of physical and psychological complications and morbidity and the influence on their social relationships. The measures to be used in such a study would need to be determined in collaboration with patients and health care professionals to ensure optimal relevance in this population. Potential measures could involve biological measures such as HbA1c, C-peptide; psychological measures such as illness perception (Oris et al. 2016), diabetes distress (Fisher et al. 2016), depression (Derogatis and Melisaratos 1983), acceptance (Schmitt et al. 2014a, Schmitt et al. 2015), self-worth (Crandal 1973);

and social measures such as status of functional and structural relationships (Joensen et al. 2016) work situation (Sheehan 2000), and overall quality of life measures (Pickup and Harris 2007, Cooke et al. 2013). Also, adding measures of self-management behaviours (Schmitt et al. 2013, Mulcahy et al. 2003) would enhance the knowledge that such studies would add about causal pathways between the bio-psycho-social aspects and their influence on diabetes related behaviours. It would further add to the knowledge base if such a study could be international, involving samples from various cultures and health care systems to enhance the contextual knowledge in relation to adapting to type 1 diabetes in the adult onset population.

Conclusion

This longitudinal interview study involving 30 adults from the UK and Denmark who were diagnosed with type 1 diabetes within the previous three years has highlighted that adapting to a life with diabetes is a complex and multifaceted process influenced by the experiences people have prior to their diagnosis and at the time of the diagnosis itself and the support they receive following this. The adaptive process identified in the study seems to happen in connected phases that are not linear but in some sense circuitous and ongoing. These phases are: transitioning from their past life experience; learning about diabetes; and reconciling their past, present and future as they learn to live a life as a person with type 1 diabetes. The data suggest that the underlying phenomena that may contribute to this adaptive process are: their prior life experiences; their understanding of diabetes; their emotional responses to the diagnosis; the way diabetes is introduced to them and their ongoing interactions with health care professionals; the expectations placed on them and those they place upon themselves in relation to their diabetes control and behaviours; their experience of the physical elements of the disease; their perception of the impact diabetes has on their lives; their interactions with others (family and friends and the wider public); their perception of how others view them; and the extent to which they accept diabetes as part of themselves. From the findings it is evident that these biological, psychological and social adaptive processes are interconnected and need equal consideration when supporting adults recently diagnosed with type 1 diabetes. However, the study has

identified that many of the psycho-social needs in the adult onset population are currently not met within the healthcare system. Consequently, the study has identified potential areas for intervention and proposed a number of modifiable elements and models to provide more adequate support to this population.

Overall this study has provided important new insights into the experiences and needs of adults recently diagnosed with type 1 diabetes which may help enhance the care for this neglected and important population.

Appendix A Examples of synthesis of first and second order constructs to third order constructs

Source studies	First order constructs (Direct quotes from source studies)	Second order constructs (Themes identified by the authors in the source studies)	Third order constructs (Constructs developed from synthesis of the source studies)
7	<i>"When I went to the hospital they take me inside, checking blood, and they tell me that I am diabetic type 1, and I was surprised really, I did not expect that, my body is not like a diabetic person"</i>	Emotional response following the diagnosis	Disruption (Physical disruption)
2	<i>"I was the strong one in the family. And suddenly I'm this diabetic, and it's really hard to accept that you're not as healthy as you thought you were. I'd always thought I was very lucky, and I never felt restricted about anything"</i>	Confrontation between identity and diabetes	Psychological disruption
5	<i>"People stopped asking what you did at work or if you had fun when you last met your mates and instead only asked how you felt and what the blood sugar readings were"</i>	The struggle not to become one's disease is a sole responsibility	Social disruption

Source studies	First order constructs (Direct quotes from source studies)	Second order constructs (Themes identified by the authors in the source studies)	Third order constructs (Constructs developed from synthesis of the source studies)
Constructing a personal view of diabetes			
9	<i>"It's not really that bad, it's just annoying you know, the time it takes"</i>	Reducing the seriousness of diabetes	Perception of diabetes
8a	<i>"Thoughts about my diabetes take up seventy-five percent of my time awake each day"</i>	Negotiating self-management that fits into life	Association and dissociation
Re-constructing a view of self			
2	<i>"Your whole opinion of yourself changes, everything changes. It's not just physically; mentally it really kind 'a throws you off. Like I don't think I lost self-confidence but it just changed my way of thinking. Like I'm not what I thought I was"</i>	Confrontation between identity and diabetes	Diabetes and self-identity

Source studies	First order constructs (Direct quotes from source studies)	Second order constructs (Themes identified by the authors in the source studies)	Third order constructs (Constructs developed from synthesis of the source studies)
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6	<i>I think, you know you can be a victim, you can enjoy that kind of ' oh everyone will feel sorry for me now because I've got that or whatever you've got' and really make a meal of it 'Oh no we can't do that because I've got diabetes, so we'll have to do this because ... ' I don't like to, I mean I will, if I really have to I will, but you know I don't want to, I'm not really a victim anyway. I think that's a kind of personality that you can have, but maybe I just identify with that because I could be like that so I don't want to be like that, so "" or even a martyr to it really, You know, it can fill a role in your life, you know, you could start manipulating everybody with it"</i>	Diabetes in daily life	Views of others
8b	<i>"I feel like a very bad diabetic person when I buy pizza"</i>	Personal beliefs	The diabetes dilemma

Source studies	First order constructs (Direct quotes from source studies)	Second order constructs (Themes identified by the authors in the source studies)	Third order constructs (Constructs developed from synthesis of the source studies)
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"It is not the fact that I have to take shots, that is particularly hard, but that people have to treat you in a special way because you take shots that is the hardest. That I am not a different person and that I am neither kinder nor more stupid and strange just because I fell ill"

The struggle not to become one's disease is a sole responsibility

Diabetes impact on life context
Stigma

9

"...because if you are working you have to wash your hands, it's filthy. It's working on the walls, its freezing over there. On the job there's nowhere to wash your hands. It's all right now. Definitely not testing as much"

Reaching goals and mis/managing illness

Life structure

8a

"My parents can never talk to me about anything other than...how my diabetes [management] is going"

Social support

The influence of significant others

Source studies	First order constructs (Direct quotes from source studies)	Second order constructs (Themes identified by the authors in the source studies)	Third order constructs (Constructs developed from synthesis of the source studies)
4			Learning to live with diabetes
	<i>"But then it was a case of I probably didn't learn about, learn a lot about, it just because I didn't want to"</i>	Knowledge	Learning to learn
1	<i>"My GP was all for me to learn to adjust my own insulin. This made a big difference in how I view diabetes...It would have been harder to accept if he tried to tell me everything I should be doing"</i>	Control	Learning support
7	<i>"I would eat half of what I would normally eat thinking oh god too much sugar or something not realising that I could eat things like that. It was one of those; it took me quite a while, ages"</i>	Strategies to support self-management	Learning through experience

Source studies	First order constructs (Direct quotes from source studies)	Second order constructs (Themes identified by the authors in the source studies)	Third order constructs (Constructs developed from synthesis of the source studies)
5	<i>"You painted horror scenarios, that I would never more be allowed to eat junk food, sweets or drink lemonade, but instead only have to eat beans and broccoli. Of course it does not work that way. I allow myself sweets sometimes, but in general I have stopped which is essentially good"</i>	To become a person with diabetes and encounter a changed life situation	The learning flux
5	<i>"There are some problems with having diabetes. You have to have regular mealtimes and you cannot be sloppy about it. So it becomes a problem when you are away at a party, when perhaps it goes a little bit longer between meals"</i>	To become a person with diabetes and encounter a changed life situation	Behavioural adaptation

Appendix B Letters of approval from NHS research ethics committee



17/07/2015

Dear [REDACTED]

Title: An exploratory study to develop a supportive PROgramme of CarE for adult onsEt type 1 Diabetes - the PROCEED study

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

- **R&D Number:** RJ115/N206
- **Ethics Number:** 15/NW/0528
- **Sponsor:** King's College London School of Medicine
- **Funder:** Foundation of European Nurses in Diabetes (FEND), The Florence Nightingale School of Nursing & Midw
- **End Date:** 01/05/2017
- **Protocol:** v1 13/04/2015
- **Site:** [REDACTED]
- **R&D Approval Date:** 20/07/2015
- **Chief Investigator:** Dr David Hopkins
- **CSP Ref:** 156457

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation as listed in the ethics letter of favourable opinion letter dated 23/06/2015. I am pleased to inform you that we are approving the work to proceed within [REDACTED] and that the study has been allocated the Trust R&D registration number RJ115/N206. I can confirm that from the SSI application form you have agreed to recruit **7 participants** within **2 years**.

Latest updated documents include:

Document	Version	Date
Topic Guide	V1	13 April 2015
Letter of invitation individual interview	V1	13 April 2015
Letter of invitation focus group interview	V1	13 April 2015
Letter of invitation workshops	V1	13 April 2015

Consent form	V2	16 June 2015
Participant information sheet individual interview	V2	16 June 2015
Participant information sheet focus group interview	V2	16 June 2015
Patient information sheet workshops	V2	16 June 2015
Research Protocol	V1	13 April 2015
Validated questionnaire	V1	20 May 2015

The research sponsor or the Chief Investigator, or the local Principal Investigator, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

Conditions of Approval:

- The principal investigator must ensure that the recruitment figures are reported.
- The principal investigator must notify R&D of the actual end date of the project.
- R&D must be notified of any changes to the protocol prior to implementation.
- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management.
- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.

Data Protection:

Please ensure that you are aware of your responsibilities in relation to The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.

The Principal Investigator is responsible for ensuring that Data Protection procedures are observed throughout the course of the project.

Amendments:

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

ISRCTN registration:

If appropriate it is recommended that you register with the Current Controlled Trials website <http://isrctn.org/>. Find out more about registering for an [International Standard Randomised Controlled Trial Number](#) (ISRCTN) as part of the Portfolio application process. Non-commercial studies with an interventional component that are eligible for NIHR CRN support can register for an ISRCTN for free via the Portfolio Database.

Should you require any further information please do not hesitate to contact us.

Thank you for registering your research project.

Yours sincerely



Liz Smith
R&D Governance Co-ordinator

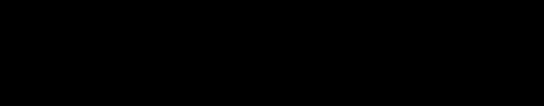
RES Committee North West - Greater Manchester South

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7704

23 June 2015

Dr David Hopkins



Dear Dr Hopkins

Study title:	An Exploratory Study to Develop a Supportive PROgramme of CarE for Adult Onset Type 1 Diabetes- the PROCEED study.
REC reference:	15/NW/0528
IRAS project ID:	156457

Thank you for your letter of 17 June 2015, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Miss Helen Penistone, nrescommittee.northwest-gmsouth@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

A Research Ethics Committee established by the Health Research Authority

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional indemnity policy schedule]		01 August 2014
Interview schedules or topic guides for participants [Topic	1	13 April 2015

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guide]		
Letter from funder [Mette Due-Christensen funding letter]		14 January 2015
Letters of invitation to participant [Letter of invitation individual interview [REDACTED]]	1	13 April 2015
Other [MetteHonConPassPort]		18 February 2014
Other [Letter of invitation individual interview [REDACTED]]	1	13 April 2015
Other [Letter of invitation focus group interview [REDACTED]]	1	13 April 2015
Other [Letter of invitation focus group interview [REDACTED]]	1	13 April 2015
Other [Letter of invitation workshops [REDACTED]]	1	13 April 2015
Other [Letter of invitation workshops [REDACTED]]	1	13 April 2015
Other [Lone working policy]		02 June 2014
Other [NRES Committee Northwest]		17 June 2015
Participant consent form [Consent form [REDACTED] version 2]	2	16 June 2015
Participant consent form [Consent form [REDACTED] version 2]	2	16 June 2015
Participant information sheet (PIS) [Participant information sheet individual interview [REDACTED] version 2]	2	16 June 2015
Participant information sheet (PIS) [Participant information sheet individual interview [REDACTED] version 2]	2	16 June 2015
Participant information sheet (PIS) [Participant information sheet focus group interview [REDACTED] version 2]	2	16 June 2015
Participant information sheet (PIS) [Participant information sheet FGI [REDACTED] version 2]	2	16 June 2015
Participant information sheet (PIS) [Patient information sheet workshops version 2]	2	16 June 2015
Participant information sheet (PIS) [Participant information sheet [REDACTED] workshop version 2]	2	16 June 2015
REC Application Form [REC_Form_08062015]		08 June 2015
Research protocol or project proposal [Research Protocol Mette Due-Christensen]	1	13 April 2015
Summary CV for Chief Investigator (CI) [Hopkins 2 page CV]		13 April 2015
Summary CV for student [CV Mette Due-Christensen]	1	13 April 2015
Summary CV for supervisor (student research) [Angus Forbes CV]	1	13 April 2015
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Project diagram of study]	1	13 April 2015
Validated questionnaire [Questionnaire for PROCEED]	1	20 May 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

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- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

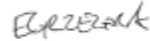
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/NW/0528	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



**On behalf of
 Professor Sobhan Vinjamuri
 Chair**

Email: nrescommittee.northwest-qmsouth@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Professor Angus Forbes



Appendix C Patient information sheet

PARTICIPANT INFORMATION SHEET

Developing support to adults with new onset type 1 diabetes

16th June, 2016

Invitation to take part in an interview study

We would like to invite you to take part in a study that will explore the views and experiences of people recently diagnosed with type 1 diabetes to help find better ways of providing health care support. Before you decide we would like you to understand why the study is being done and what it would involve for you. We will go through the information sheet with you and answer any questions you have, should you be interested in participating. Talk to your family, friends, doctor or nurse if you wish.

This information sheet tells you the purpose of this study and what will happen if you take part, and gives you detailed information about the conduct of the study. Please ask us if there is anything that is not clear.

What is the purpose of the interview study?

The study aims to investigate how adults who are diagnosed with type 1 diabetes learn to live with diabetes, what challenges they face and in what way diabetes may affect them. In addition, we would like to identify what kind of support is viewed as beneficial and what else might be helpful during this time. We would like to develop a package of support for adults with new onset type 1 diabetes to help them to learn to live with type 1 diabetes. Before we do this, we need to find out what adults with new onset type 1 diabetes would find helpful.

We will hold some interviews with adults who have been diagnosed with type 1 diabetes. In the interviews we would like to ask you about your experience of being diagnosed with type 1 diabetes, how you live with diabetes, and the support you have needed. After the interview we will give you a questionnaire to be filled out concerning your experience of living with diabetes. In addition to this we would like to retrieve information from your medical record on type of treatment and blood glucose control.

Why have I been invited?

We are inviting adults who have been diagnosed with type 1 diabetes within the last three years, and attend [name of clinic] for their diabetes care. We are looking for around 15 adults to take part in this study.

Do I have to take part?

It is up to you if you decide to take part in the study. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of any care you would receive at the hospital.

What will happen to me if I take part?

We will invite you to participate in two interviews that will last approximately 1 hour each. The first interview will be conducted within one month of your agreeing to participate in the study and the second interview will be conducted approximately 6 months later. You will be encouraged to share your experiences with the researcher. The researcher will use a prompt sheet to facilitate the interview and an audio tape will be used to tape the interview. The interview can take place at the hospital, in your home or at another location according to your preferences. After the interview you will be asked to fill out a questionnaire. It will take approximately 20 minutes to fill out and it is voluntary to do so.

Patient information sheet version 2 16/6 2015

Expenses and payments

We will give you a £25 gift voucher for participating in each interview to cover any expenses you might have in relation to this.

Benefits of taking part

We cannot promise that participating in the study will help you. However, the possible benefits of taking part in the interviews are:

- You will be contributing to the design of a programme of support for adults with new onset type 1 diabetes
- You may learn more about your own experiences of having diabetes by sharing your story with the researcher

What if there is a problem?

We do not anticipate that participation in the study will cause any problems. However, you will be reflecting on your experiences and this could be upsetting. We will conduct the interviews in a supportive way and should any problem arise during the interview, we can with your permission, contact relevant people in the health care team to help you address these problems. If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact Mette Due-Christensen on [phone number]. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service on [phone number].

What happens after the interview?

The things said on the recording will be typed out and the recording will be destroyed and the researcher will analyse it along with the other interviews that have been conducted. The findings from the analysis will help design a programme of support for adults with new onset type 1 diabetes.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The interviews will be audio recorded and then written down. The information you provide will remain anonymous and no comments you make will be attributable to you or affect the care you receive in anyway.

Who is organising and funding the research?

The researcher is conducting this study as a PhD project at Faculty of Nursing and Midwifery, King's College London. The study is funded by Foundation of European Nurses in Diabetes.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NRES Committee Northwest GM South.

Further information and contact details

For further information and any enquiries relating to the study, please contact:

Mette Due-Christensen
PhD candidate
Phone: [phone number]
Email:mette.due-christensen@kcl.ac.uk

[Name of nurse]
Nurse Consultant: Diabetes
Phone: [phone number]
Email:[name of nurse]@nhs.net

Appendix D Letter of invitation

Dear

As part of a PhD in nursing at King's College London, Mette is conducting a research study to investigate how adults who are diagnosed with type 1 diabetes learn to live with diabetes, what challenges they face and in what way diabetes may affect them. The result of this study will help inform ways to develop a package of support for adults with new onset type 1 diabetes to help them to learn to live with type 1 diabetes and come to terms with the disease. Before we do this, we need to find out what adults with new onset type 1 diabetes would find helpful. We are contacting you as you are eligible to take part in the study and to see if you would be interested in helping in this research project.

The study involves taking part in two interviews with approximately 6 months interval and answering a questionnaire. The interviews can take place either at the hospital, in your home or at another location according to your preferences. Taking part in the research is voluntary and if you prefer not to do so nobody will be upset and your treatment will not be affected.

If you would like to hear more about the study, or if you are interested in taking part, please read the enclosed information sheet and contact the researcher by email (mette.due-christensen@kcl.ac.uk) or phone [phone number] or by returning the reply slip below in the stamped addressed envelope provided or to the diabetes specialist nurse. Mette will contact you to discuss the study. Replying by email or returning the slip does not commit you to take part, only to find out more about the study.

Thank you for taking the time to read this information.

Kind regards,

Ms Mette Due-Christensen
Researcher

Ms NN
Diabetes Specialist Nurse

*Please tick the appropriate box and return this page in the stamped addressed envelope provided
Please return this slip even if not interested in the study – thank you*

Name _____

Best contact phone or email: _____

YES – I agree to be contacted further about this study

☐

NO – I do not agree to receive any further information in relation to this study

☐

Please return in the stamped addressed envelope provided

Letter of invitation version 1 13/05 2015

Appendix E: Interview guides

First round of interviews:

- Can you tell me about what happened when you were diagnosed with diabetes?

Prompt: How did you feel, how did people around you react, and what was it like starting medical treatment?

- In what way, if any, has diabetes made a difference to your life compared to how it was before you were diagnosed?

Prompts: What would you say has changed? E.g. relationships, thoughts/views about yourself and/or others, plans for the future.

- How has being diagnosed with type 1 diabetes affected how you view yourself?

- What do you find is the hardest thing about having diabetes?

Prompt: Has that changed over time and in what way?

- Would you say that you have come to terms with diabetes? In what way? How did you achieve this?

- In what way have your previous experiences of coping with things you find difficult in life affected your strategies for coping with diabetes?

- What was the most/least helpful thing that happened following your diagnosis with diabetes?

- What kind of support, if any, have you received?

Prompt: from family, friends, work, others, the health care system.

- What kind of support do you think should be offered to an adult who is diagnosed with diabetes?

- Is there anything else you would like to tell me?

Second round of interviews

- What do you think is the most important thing that has happened in relation to your diabetes since our last conversation?

- When you look back at this point what difference do you think diabetes has made to your life compared to how it was before you were diagnosed?

Prompts: What would you say has changed? E.g. relationships, thoughts/views about yourself and/or others, plans for the future.

- With the experience of living with diabetes that you now have, what difference has being diagnosed with type 1 diabetes meant in relation to how you view yourself?

- At this point, what do you find is the hardest thing about having diabetes?

Prompt: Has that changed over time and in what way?

- Would you say that you have come to terms with diabetes? In what way? How did you achieve this?

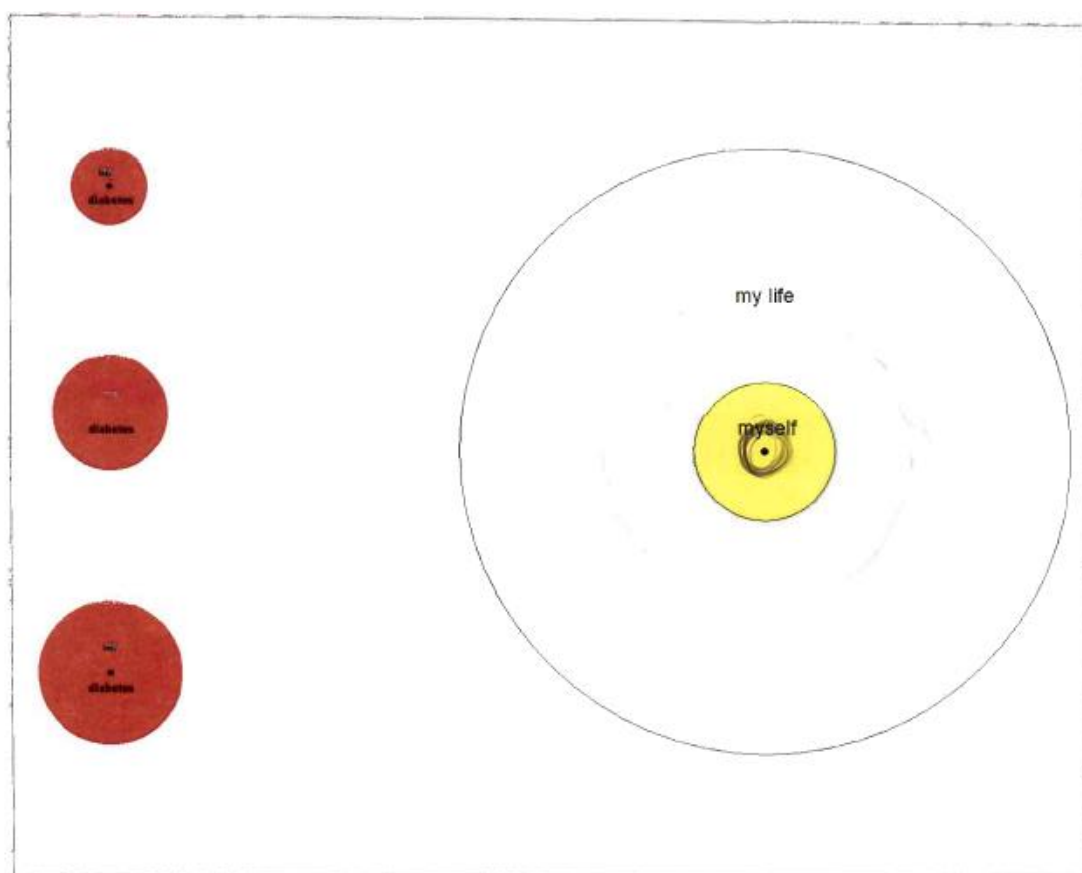
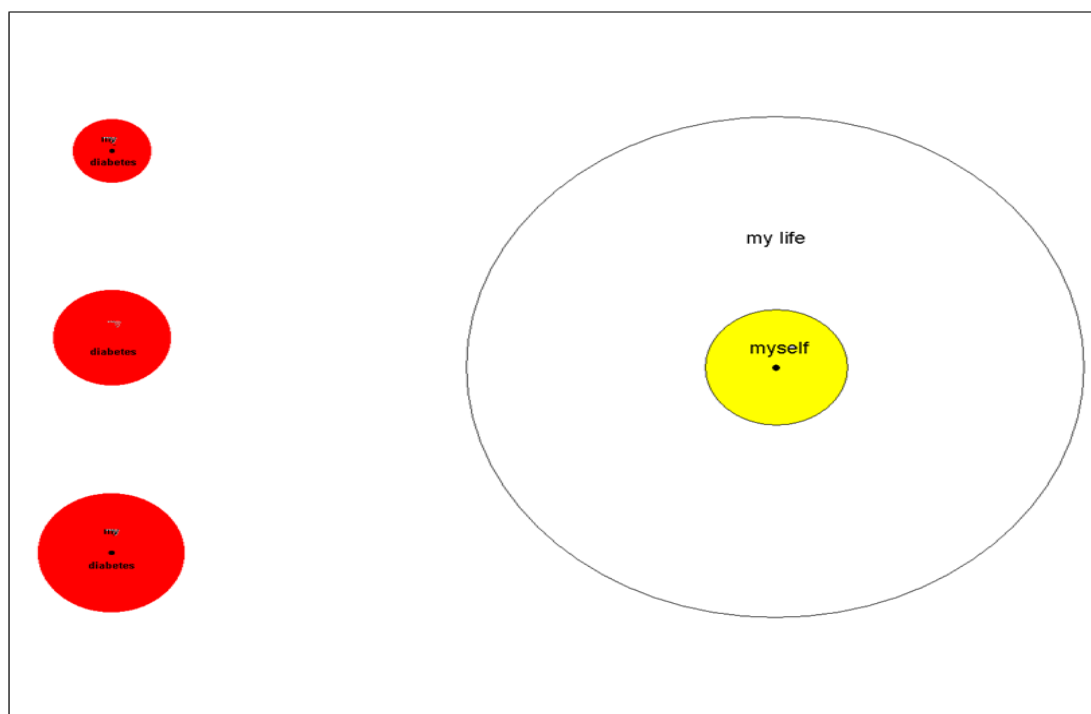
- What kind of support, if any, have you received since our last conversation?

Prompt: from family, friends, work, others, the health care system.

- Is there anything else you would like to tell me?

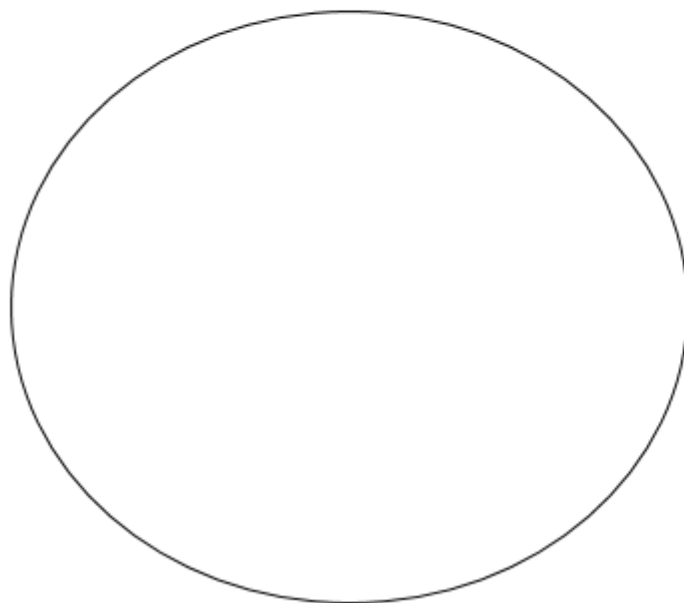
Appendix F Dialogue tools

Blank example on top and example of completed tool below

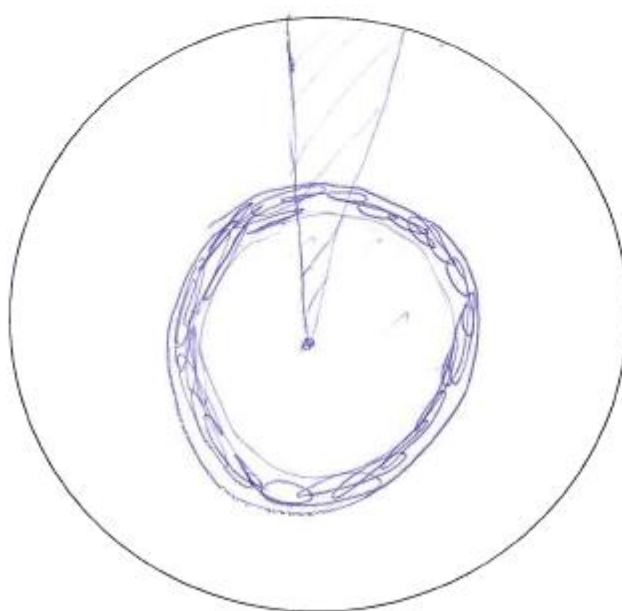


Blank example on top and example of completed tool below

If the whole circle represents your life how much space does diabetes take up?



If the whole circle represents your life how much space does diabetes take up?



Appendix G Consent form

CONSENT FORM

Development of support to adults with new onset type 1 diabetes

Researcher: Mette Due-Christensen, PhD student, Florence Nightingale Faculty of Nursing and Midwifery, King's College London, 57 Waterloo Road, Room 4.26, London, SE1 8WA

Please initial box

- | | |
|--|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated <u>16.06.2015 (version 2)</u> for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by the researcher (Mrs. Mette Due-Christensen), where it is relevant to my taking part in this research. I give permission for Mrs. Mette Due-Christensen to have access to my records. | <input type="checkbox"/> |
| 4. I understand that my data and data collected from the study may be looked at by regulatory authorities, by persons from the trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information. | <input type="checkbox"/> |
| 5. For the purpose of data collection I agree to be audio taped. | <input type="checkbox"/> |
| 6. I agree to direct quotes being used in the research reports as long as I cannot be identified. | <input type="checkbox"/> |
| 7. I agree to take part in the above study. | <input type="checkbox"/> |

_____ Name of participant	_____ Date	_____ Signature
------------------------------	---------------	--------------------

_____ Name of researcher	_____ Date	_____ Signature
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Version 2 16/06 2015

Appendix H Field notes

Mark, early thirties, diagnosed 28 months ago (from Denmark)

Mark had not replied to the invitation letter, so I called him on his cell phone. He was immediately aware of the invitation and agreed to participate in the interview. We made an appointment for the following week at his house, as he was on parental leave. When I arrived at his house the door was not opened. I decided to wait for a few minutes as I knew he was minding a baby and then tried ringing the bell once more. This time the door was opened by Mark holding his baby in his arms. He had completely forgotten about the interview and I offered to come back another day. He declined and invited me in. The baby had just had a bath and he cared for her and then we were able to start the interview. As the baby was awake most of the time the interview was interrupted from time to time, but Mark was quick to return the questions that had been asked or follow up on his own comments.

Things to learn: Be mindful of closed questions. When summing up remember to ask if that is a reflection of what the person has said.

Jane, mid-twenties, diagnosed 5 months ago (from the UK)

Jane had replied by email to the invitation letter. I sent the PIS and we agreed to speak on the phone after she had had a chance to read it. She agreed to participate, and we set up an interview for the next evening after she got off work. We met at the clinic she attends, and the interview was conducted in a meeting room. Jane made an effort to speak slowly and clearly and even though I had assured her that there are no right or wrong answers she was very careful not to be critical of any of the things she had experienced.

Things to learn: Reiterate that it is the personal experiences that are the focus of the interview.

Appendix I Summaries

Mark, early thirties, diagnosed 28 months ago (from Denmark)

Short summary of the first interview held in his home:

Mark found that health care support was lacking in the beginning and hence tried to manage himself during the first weekend after the diagnosis, and was reluctant to attend clinical appointments initially. Since then he has received a lot of support from one specific nurse whom he feels has taken an interest in him and his family. He would like to be able to understand the pathophysiology of diabetes, but he feels he is not getting answers when he asks about what is going on in his body. He aims to prove that everything is possible, and diabetes is not a restriction, even though he also says it is. He has difficulties with low blood glucose and has experienced several instances where he has been in need of help – among others from his oldest child (7 years) and from colleagues – but keeps up his quest for the low values. He eats the same types of food and finds that helps to manage his blood glucose. He does a lot of exercise, which has been a challenge since the diagnosis. A nurse put him in contact with two other men who had also experienced challenges with exercise which he thinks has been very helpful. He feels acceptance is a process regarding what can be done and what can't be influenced.

Short summary of the second interview conducted as a phone interview:

Changing types of long acting insulin has been the biggest change since our last conversation. Mark's blood glucose levels are fluctuating less since the change. He has also had a consultation with a nutritionist and runs his diet very strictly still, which has helped him to increase his level of exercise. The combination of these things means that he has cut his insulin by about 50% which he feels makes management easier and consequently he has fewer episodes of hypoglycaemia. While he still has such episodes, he is able to detect signs of cognitive impairment earlier on and feels he understands more about them. Having hypos in front of others and requiring their help is still something he feels embarrassed about. His way of managing his diabetes is a good way

for him but he feels other have difficulties accepting how he goes about it. He is especially annoyed when people try to tell him about diabetes when they don't actually know much about it. Mark has changed his job and finds his new colleagues more understanding which has helped him manage his diabetes. Mark mentions that all the hypos he has had have led him to realise that he is not getting rid of diabetes. He also mentions that diabetes helps him to stay motivated to live the kind of life that he now does. Finally, Mark mentioned the limitations and how he feels that although he wants to show everyone and himself that diabetes is not stopping him there are limitations.

Jane, mid-twenties, diagnosed 5 months ago (from the UK)

Summary of the first interview held in a meeting room in the clinic Jane attends:

Jane believes her transition into diabetes was very different from most people because she did not experience DKA. However, she described the usual symptoms and care pathway. She talked about the theory of diabetes – that it seems easy, but it is hard. However, she finds it difficult to explain what is hard about having diabetes. She is trying to prove that she can do everything she wants and finds that planning is essential for doing that. She also mentioned thoughts about future complications and that she needs to manage her diabetes well to avoid those. She is reluctant to involve her friends too much in her diabetes. It is difficult for her to talk about diabetes and she describes how it may also affect others. She finds the support she has had from the health care professionals has been good.

Summary of the second interview conducted as a phone interview:

One year after her diagnosis Jane feels that managing diabetes has become more of a routine but also finds it challenging that diabetes doesn't always behave in the same predictable way. Adjusting to food and exercise has come with experience, but again needs constant adjustments. This challenge is difficult for her to explain to people around her. The first six months involved a steep learning curve, but she is now learning more through daily living. Participating on a DAFNE course has been beneficial, especially seeing other people with long and short durations of diabetes and learning

from them. Applying the DAFNE rules hasn't always been easy, possibly because she is still in the honeymoon phase. Even though she is not as hard on herself as previously when her blood glucose level is high, she feels rubbish when it's high and has difficulties accepting that it is okay sometimes, as it is not okay for "normal" people to have blood glucose values in that range. She feels she accepted diabetes early on and that mostly she is feeling fine and diabetes hasn't made any great change to her life other than she has to plan a bit more than before and make sure she is prepared when doing activities. There have also been positive things and she has done things and met people she wouldn't have if she didn't have diabetes.

Appendix J NVivo thematic coding

Nodes for Diabetes

DIABETES	52	507
VIEW OF DIABETES (what is diabetes)	51	337
Unfamiliar disruption	8	10
Comparing diabetes to other things in life	8	10
Multiple faces of diabetes	37	134
Disease or condition	19	37
Diabetes is annoying	17	29
Diabetes as an acting agent	8	18
A trigger for change	24	50
Positive things about diabetes	24	50
Diabetes is relentless	28	62
The theory of diabetes (a complicated equation)	5	11
Diabetes is always there	23	44
IMPACT OF DIABETES (what has diabetes done)	43	170
The shittiness of having diabetes	5	6
Limitations	21	42
Spontaneity	12	17
Freedom	5	7
Diabetes is not stopping me	19	29
How has diabetes affected your life	35	122

Nodes Bio-Psycho-Social framework

BIOLOGICAL	54	698
Alternative way of being diagnosed	6	7
Being faulty or weak	11	19
Type 2	16	28
Cure for diabetes	9	10
Comparison with other diseases	25	53
DKA	8	13
Doubts of diabetes type	8	14
Getting diabetes again	3	3
Handling high blood glucose	22	33
HbA1C	14	23
Honeymoon	28	55
Pump	9	16
Seriousness of diabetes	41	131
Starting insulin	19	29
Suffering from other chronic diseases	6	15
Hypoglycaemia	36	96
Initial physical symptoms	24	44
Lack of trust of own body	12	16
Ongoing insulin treatment	29	63
Physical symptoms not related to diabetes	7	9
Prediabetes thoughts of what was wrong	12	21

PSYCHOLOGICAL	56	1343
Worst thing	36	46
Why did I get diabetes	25	61
View of self	45	324
Stress	4	7
Self-concept	17	36
self-blame	15	26
self worth	2	2
Room for diabetes	31	39
Responsibility	2	5
Rebellion against diabetes	7	7
Psychological support	31	66
Proximity of diabetes	29	38
Motivation	5	17
Losses	8	13
Interruptions because of diabetes	10	19
Initial thoughts about diabetes	22	53
Initial reaction to diabetes	21	41
Grief	12	21
Feeling stressed	12	16
Feeling sad	2	2
Feeling relieved by the diagnosis	6	10
Feeling of immortality	6	9
Feeling guilty	3	3
Feeling good despite diabetes	1	1
evaluation of own story	7	10
Emotional support	19	40
Emotional adaptation	27	64
Denial	9	17
Crying and feeling overwhelmed	13	19
Coping with other difficulties	26	37
Comparing with other people with diabetes	29	84
Coming to terms and acceptance	45	128
Carrying diabetes stuff	17	27
Being normal	22	36
Being difficult because of diabetes	2	2
Being different	12	17

SOCIAL	55	588
Work	28	58
Support 2	1	1
Social support	23	62
Social implications	25	47
Relationships and diabetes	7	13
Peer support	43	113
Partner reactions	10	21
Other people's reaction to diagnosis	19	26
Openness about diabetes	34	70
Knowing others with T1DM	16	29
Ignorance of diabetes	19	33
Explaining what diabetes is	15	23
Early support from family	22	47
Diabetes loneliness	5	6
Diabetes impact on friendship	6	11
Communicating diabetes	12	23
Advocacy for diabetes	1	5

In text coding

Final version 1 and 2 interview.nvp - NVivo

File Home Create External Data Analyze Query Explore Layout View

Navigation View Find Quick Coding Detail View Close All Dock All Undock All Bookmarks Close Window Docked Zoom Layout List View List View Coding Stripes Highlight Annotations See Also Links Relationships Node Node Matrix Framework Matrix Classification Report Previous Next Color Scheme Visualization

Nodes

Look for: Search In Nodes Find Now Clear Advanced Find

Nodes

Name	Sources	References	Created On	Created By	Modified On	Modified By
biggest changes 2	2	2	02/10/2016 17:25	KCL	06/11/2016 07:45	KCL
BIOLOGICAL	54	698	05/04/2016 15:20	MDC	21/10/2016 16:56	KCL
DIABETES	52	507	05/04/2016 15:12	MDC	21/10/2016 16:56	KCL
Hope for the future	1	2	21/10/2016 16:41	KCL	06/11/2016 07:45	KCL

Lisa

perspective of, if I can deal with diabetes and a condition that people don't know I have I can deal with most things and it makes you ultimately a stronger person and if someone doesn't find that interesting about you then like they can do one, so [Laughter]

I think like I struggled with initially the social thing of people, I think as well with personal relationships so to do with men I worried like 'oh will they think of me badly because I have diabetes or this very complex being' or that they'd see me as faulty in some way and that was really hard for me to come to terms with and then something just clicked where I just thought 'actually if I was in their shoes' and most people don't know that much about it so it's not really a big deal anyway and if it is then they don't see it for the good that it is because I do a hell of a lot and I manage myself a lot and I have a level of appreciation and understanding and it creates more empathy within me and stuff and I think if they don't see the good in that then they don't deserve to be in my life. So jog on. [Laughter]

Explaining what diabetes is
Temporal sequence of diabetes
Learning about diabetes - knowledge
Interactions with HCPs
Suggestions for improvement of care
Admission to hospital
Early support from family
Learning to live with diabetes
View of diabetes (what is diabetes)
Learning about diabetes
Initial physical symptoms
Coming to terms and acceptance
View of self
Impact of diabetes (what has diabetes done)
How has diabetes affected your life
DKA
Diabetes
Biological
Social
Psychological
Lisa
Coding Density

In Nodes Code At

KCL 136 Items Linked Nodes: 76 References: 287 Editable Line: 1 Column: 0 100% 13:39 05/05/2017

Appendix K Dissemination of research

Dissemination of research findings through publication and conference presentations is imperative if the research is to make a wider impact and influence the field of research. The dissemination of the findings that have already taken place can be seen in table 6 and the plans for further dissemination are outlined in table 7 below.

Table 6 Dissemination to date

Year	Type of presentation	Conference
2017	Poster presentation	Diabetes UK
	Poster presentation	ADA (in June)
2016	Key note presentation	FEND
2015	Poster presentation	IDF
	Poster presentation	Diabetes UK
	Key note presentation	FEND
	Poster presentation	EACH summer event
2014	Poster presentation	FEND
	Oral presentation	PSAD

Table 7 Plan for future dissemination of research findings

Type of work	Potential audience/journal
Abstract submitted	EASD
Presentations planned:	National Adult Type 1 Diabetes meeting (October 2017) Alliance for Diabetes Self-Management and Prevention (November 2017)
Papers planned:	
1. Literature and Meta-synthesis	Submitted to Qualitative Health Research
2. An exploratory study of the experiences of being diagnosed with type 1 diabetes in adulthood	Diabetic Medicine
3. The honeymoon experience from the perspective of adults recently diagnosed with type 1 diabetes	Diabetologia
4. Diabetes: a life drawing. Using dialogue tools in research	Journal of Advanced Nursing

Abbreviations

A&E	Accident and Emergency
AA	Alcoholics Anonymous
CASP	Critical Appraisal
CGM	Continuous Glucose Monitoring
CRN	Clinical Research Network
DAFNE	Dose Adjustment For Normal Eating
DCCT	Diabetes Control and Complications Trial
DKA	Diabetic Ketoacidosis
EDIC	Epidemiology of Diabetes Interventions and Complications Study
GP	General Practitioner
HbA1c	Glycated haemoglobin
MeSH	Medical Subheading
Mmol/l	Millimoles pr Litre
Mmol/mol	Millimoles pr Mol
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NIHR	National Institute for Health Research
PPI	Patient and Public Involvement
SOC	Sense of Coherence
WHO	World Health Organization

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